

# *Monitoring Infants and Children with Special Health Needs*

**Birth Defects Prevalence and Mortality  
in Michigan, 1992-2002**



*Michigan Department  
of Community Health*



Jennifer M. Granholm, Governor  
Janet Olszewski, Director

March 2005

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# *Monitoring Infants and Children with Special Health Needs*

## **Birth Defects Prevalence and Mortality in Michigan, 1992-2002**

*A report prepared by*

- **Michigan  
Department of  
Community  
Health**
- **Bureau of  
Epidemiology**

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March 10, 2005

Dear Colleagues and Friends:

I am very pleased to offer you this copy of the first report from our Michigan Birth Defects Registry (MBDR) summarizing important public health data on children with special health needs. The report is the result of ongoing collaborative efforts between staff from the Registry, Maternal-Child Health Epidemiology Unit, and Public Health Genomics Program in the Bureau of Epidemiology as well as the Children's Special Health Care Services Program in the Bureau of Family, Maternal and Child Health.

The Michigan Department of Community Health has been fortunate to receive cooperative agreement funding from the Centers for Disease Control and Prevention (CDC) beginning in 1999 that has led to improvements in the quality of birth defects data and supported development of related prevention and intervention activities. Moreover, increased attention at the national level to birth defects surveillance and prevention spurred by the March of Dimes resulted in the creation of a national Center for Birth Defects and Developmental Disabilities at the CDC in April 2001. We are indeed grateful to the Center and the March of Dimes for their ongoing support of birth defects monitoring, prevention, and follow-up endeavors here in Michigan.

Although the causes of most birth defects remain unknown, there are many steps women of childbearing age can take to ensure their own good health during pregnancy and reduce the risk of birth defects in their future offspring. Please help us spread the word to your own family, friends, and community about the benefits of folic acid and other strategies described in the report for preventing the occurrence of birth defects.

Although approximately 10,000 Michigan babies are born each year with birth defects, we are fortunate to live in a state where dedicated professionals and considerable resources are available to assist children and their families through medical centers, specialty pediatric clinics, and community-based intervention programs. For more information on the system of supports and services available in Michigan, please contact the Registry Follow-up Coordinator at [BDRFollowup@michigan.gov](mailto:BDRFollowup@michigan.gov) or call toll-free at 1-866-852-1247.

Thank you for your thoughtful consideration of this important inaugural report and please accept my gratitude for your interest and dedication to this special group of Michigan children and the families caring for them.

Respectfully,

Kimberlydawn Wisdom, MD, MS  
Michigan Surgeon General

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# Executive Summary

This inaugural report presents an overview of the Birth Defects Program at the Michigan Department of Community Health (MDCH). The program includes three components that address monitoring, prevention, and follow-up. Statewide surveillance data from the Birth Defects Registry are also included for the birth cohort years of 1992-2002, along with in-depth analyses of four common conditions: neural tube defects (NTD), orofacial clefts, Down syndrome and congenital heart defects.

Michigan's formal surveillance system for monitoring the occurrence of birth defects began in 1987 when the public health code was amended by Act 48 to require establishment of a birth defects registry. Case reporting began in 1992. This report reviews the history of how the registry was established, and discusses the public health impact of birth defects which are a serious public health problem in the State of Michigan and across the nation.

MBDR is a passive system that relies on reporting from hospitals, cytogenetic laboratories and pediatric genetics clinics for case ascertainment. Reportable conditions include all congenital anomalies of consequence, genetic disorders presenting at

## *The purpose of the Michigan Birth Defects Registry is to:*

- ☐ Collect statistical data on the incidence of birth defects in Michigan
- ☐ Conduct birth defects surveillance and epidemiologic studies on the causes of birth defects
- ☐ Provide data for birth defect prevention and intervention efforts, program planning and evaluation
- ☐ Assure that children with birth defects and their families receive appropriate support services

birth or in early childhood, and selected maternal exposures to infectious diseases and other teratogenic agents such as alcohol. Information is collected on children from birth to two years of age who were born, diagnosed, or treated in the State of Michigan. All incoming reports are linked with birth and death records to create a case file. Fetal deaths with any of the specified conditions must also be reported. About 85 percent of case reports are submitted in electronic form with roughly half received through the electronic birth certificate and half in the form of hospital specific data files. The remainder are received as paper abstracts. Quality assurance procedures include internal monitoring for missing or invalid information and facility audits to assess statewide reporting performance.

Birth defects are a serious public health problem in the State of Michigan and across the nation. They contribute significantly to childhood mortality, morbidity, and long-term disability. During 2002, there were 10,365 children with birth defects reported to the Michigan Birth Defects Registry (MBDR) within the first year of life. This corresponds to an incidence rate of 810.2 cases per 10,000 resident live births or approximately eight percent of the annual birth cohort of 129,518 Michigan newborns.<sup>1</sup>

Children with birth defects often require care that is expensive and highly specialized. The psychosocial impact of serious birth defects is also considerable. The report examines the

mortality in children with birth defects in detail. The infant death rate for children born in 2002 with a reportable birth defect was 40.9 per 1,000 live births. This compares to an infant death rate of 7.6 per 1,000 live births for all resident infants. The data highlight and reinforce the need to address birth defects as part of public health efforts aimed at reducing infant mortality.

In the realm of birth defects, there are often more questions than answers concerning causality and prevention. However, certain strategies, such as maternal consumption of folic acid before conception and early in pregnancy, are now known to be effective in reducing the risk of neural tube defects. The Birth Defects Program promotes known prevention strategies through a variety of outreach activities including an ongoing folic acid educational campaign and by disseminating materials during National Birth Defects Prevention Month. MBDR data and other surveys are used to track progress in folic acid awareness and use among Michigan women of childbearing age. A recent study conducted by the Pregnancy Risk Assessment Monitoring System (PRAMS) of women who gave birth in 2001 concluded that, while the majority know about the sources and benefits of folic acid, less than one-third actually reported taking a daily multivitamin in the month before pregnancy.

The follow-up component of the Birth Defects Program assists families with locating available resources and support systems. Follow-up with families of infants with NTD has recently been initiated, to assure they receive available services and are aware that increased doses of folic acid are needed to reduce the chance of recurrence in future pregnancies. A genetic support group directory is maintained, and a pamphlet, *Resources for Families of Infants and Toddlers with Special Health Needs*, is widely disseminated at no cost to hospitals, early intervention providers, health professionals and others. A listing of some of these state and national resources is included at the end of the report. ■

# Introduction



The impetus for this inaugural report comes from the data collected by the Michigan Birth Defects Registry (MBDR) over the last 13 years covering more than 800 diagnoses reported on children from birth through 24 months of age. Indeed, understanding and use of birth defects data is just as important as conscientious data collection. The report therefore serves as a way to share MBDR findings with partners and stakeholders concerned about the cohort of Michigan infants and children with special health needs. A second motivating factor behind the report is the support and direction provided by the Centers for Disease Control and Prevention (CDC). The Department of Community Health has received cooperative agreement funding from the CDC since 1999 to enhance the quality of the birth defects monitoring system and to support use of data by public health programs for prevention and intervention activities. Increased emphasis on birth defects surveillance and prevention led to the creation of a national Center for Birth Defects and Developmental Disabilities (NCBDDD) at the CDC in April 2001. The State of Michigan has benefited greatly from the ongoing support for birth defects monitoring, prevention, and follow-up endeavors provided by NCBDDD. This report serves as evidence of the considerable improvements that have occurred in the MBDR over the last six years as well as the collaborative partnerships that bring together the expertise of staff members from the Vital Records and Health Data Development Section, Maternal and Child Health Epidemiology, and the Genomics program to create a comprehensive *Birth Defects Program* at the Michigan Department of Community Health.

## History of the Michigan Birth Defects Registry (MBDR)

Michigan's formal surveillance system for monitoring the occurrence of birth defects began in 1987 when the public health code was amended by Act 48 to require establishment of a birth defects registry. The legislation was subsequently updated by Act 236 of 1988 which reflects the current law on birth defects reporting. Shortly after enactment, the Michigan Department of Community Health (MDCH) began planning for the registry. Administrative rules (Rule 325.9071-9076) governing the operation of the registry were approved in November of 1991 and statewide, passive data collection began in 1992.

The delay in initiating statewide reporting was caused by the need to investigate a number of issues that would prove critical to the registry's success. There were very few statewide or even regional population-based birth defects registries in existence at that time. Most of those in operation in the late 1980s were active registries where staff visited health facilities to identify and abstract cases. While this approach is very successful, it is quite expensive. In order to establish a registry that was economical for the state, manageable for reporting facilities, and that could reasonably be expected to result in useful information, considerable review and planning were necessary.

The initial step in the planning process was to conduct a feasibility study to determine if a birth defects registry could be established in Michigan that would provide reliable information and be affordable. It was determined early on that an active registry was too expensive. It was not

clear, however, whether a passive registry would provide useful data. Birth defects information had been reportable on birth certificates; however, the accuracy of the information, in Michigan and nationwide, was known to be very poor. To further evaluate the value of a birth defects registry in Michigan, Claudia Holzman DVM, MPH was hired as a consultant to conduct a feasibility study. Dr. Holzman, now with the School of Epidemiology at Michigan State University, investigated the practices in population-based registries operating in 1988. She also consulted with experts at the Centers for Disease Control and Prevention (CDC), particularly Larry Edmonds of the Birth Defects Branch within the Center for Environmental Health. The results of Dr. Holzman's review were that such a registry was feasible and practical. The study proposed that the registry could provide birth defects prevalence, prevalence and mortality rates, trends in prevalence and mortality, and could be used to plan, develop and evaluate programs targeting birth defects while aiding in coordinating services to families. The registry could also aid in evaluating potential clusters of events and could be used for research into the causes of birth defects.

These findings led to the formation of a planning group to review a number of issues including what would be the case definition for a reportable condition; who should be responsible for reporting cases; what items of information should be collected on each case; and what methods for reporting should be available. This advisory group included departmental staff and representatives from four hospitals, listed in Appendix A. Forms were designed, a case definition was created and instructions for reporting were developed. A pilot reporting project was initiated in 1990. This involved reporting of birth defects cases by staff from seven hospitals, namely Children's Hospital of Michigan, Hurley Hospital, Mercy Memorial in St. Joseph, Community Health Center in Branch County, Henry Ford Hospital, Butterworth Hospital and E.W. Sparrow Hospital. The purpose of the pilot was to work through the reporting process and make revisions as indicated. The input from all involved parties was essential to the planning, and, it was hoped, would result in an efficient, manageable and affordable registration process.

As the mechanical aspects of the registry were being developed, other principles relative to registry operation were being devised. It was decided to make hospitals and cytogenetics laboratories primarily responsible for finding and reporting cases. Confidentiality rules were devised and refined. The process for acquiring access to these sensitive data for research or administrative purposes was also proposed by the group and later enacted into Administrative Rule.

*...the planning and the advice received during the development phase of the registry have resulted in an economical but useful source of information on birth defects in Michigan...*

The planning and the advice received during the development phase of the registry have resulted in an economical but useful source of information on birth defects in Michigan. The registry staff continue to be indebted to the careful considerations and wise counsel of the advisory panel. Since 1992, the registry has identified additional, readily available sources of information on birth defects cases and has developed alternative mechanisms for facilities to meet their reporting obligations, but the reporting process is largely unchanged. While data quality did erode during the years 1995 through 1997 due to a temporary discontinuation of facility monitoring, an active quality assurance effort was re-established in 1998, supported in part by cooperative agreement funding from the Centers for Disease Control and Prevention (CDC). This basic effort to monitor facility reporting volumes and timeliness, and to train hospital staff when indicated have

combined with conscientious efforts by reporting facilities to create a reliable and timely source of data on birth defects prevalence and mortality in Michigan.

## Public Health Impact of Birth Defects

Birth defects are a serious public health problem in the State of Michigan and across the nation. During 2002, there were 10,365 children with birth defects reported to the Michigan Birth Defects Registry (MBDR) within the first year of life. This corresponds to an incidence rate of 810.2 cases per 10,000 resident live births or approximately eight percent of the annual birth cohort of 129,518 Michigan newborns.<sup>1</sup> Birth defects contribute significantly to childhood mortality, morbidity and long-term disability. The infant death rate for children born in 2002 with a reportable birth defect was 40.9 per 1,000 live births. This compares to an infant death rate of 7.6 per 1,000 live births for all resident infants born in Michigan during 2002.<sup>2</sup> Recent analysis of MBDR surveillance data reveals that children with birth defects represent as much as 40 percent of all deaths to infants and children under age 10 years. This is significantly higher than the one in five infant deaths usually attributed to birth defects based on death records alone and highlights the lack of attention to the impact of birth defects as a cause of early childhood death.

*Recent analysis... reveals that children with birth defects represent as much as 40 percent of all deaths to infants and children under age 10 years.*

Children with birth defects often require care that is expensive and highly specialized. Support for the family and affected child may be provided not only by a primary care physician in a medical home and by a variety of medical specialists, but also by adjunct health services, the educational system, community and social organizations, and local or national agencies. In a 1992 CDC report, the economic cost per new case of significant birth defects ranged from \$75,000 for atresia/stenosis of the small intestine to \$505,000 for truncus arteriosus. The cost per case of spina bifida was estimated then to be \$294,000.<sup>3</sup> A sizeable proportion of children with birth defects are eligible for state and federal programs to subsidize their care. Data from the Michigan Children's Special Health Care Services (CSHCS) Program reveal that expenditures for 586 beneficiaries with neural tube defects (NTD) totaled \$3,729,242 in fiscal year 2002, averaging \$6,364 per child in specialty medical care alone.<sup>4</sup>

The psychosocial impact of serious birth defects is also considerable. Multiple feelings and emotions typically accompany the birth of a baby with birth defects. These may include disappointment, denial, anger, fear of the unknown, guilt, powerlessness to change what is happening, and rejection.<sup>5</sup> Regardless of the nature of the particular birth defect or its etiology, the experiences of families are similar and may require significant adaptation to the emotional and social ramifications of the diagnosis along with a substantial need for medical information, support and advocacy. Extreme financial pressures may occur. A loss of self-esteem among family members and considerable change in roles and responsibilities further complicate household dynamics. While all families do not necessarily experience all of the challenges described, it is not surprising that families of children with birth defects are often affected by higher rates of marital discord, financial setbacks, and difficulties in raising the affected child's siblings.<sup>6,7,8</sup>

# Michigan's Birth Defects Program

## Overview

Michigan's Birth Defects Program encompasses three important components: *monitoring*, *prevention*, and *follow-up* (See Appendix B).

### Monitoring

Statewide monitoring of birth defects is conducted by the MBDR. The confidential registry is a passive system of ascertainment that relies on reports submitted by all Michigan hospitals and cytogenetic laboratories within 30 days of a child's diagnosis. Over 860 reportable conditions include structural malformations as well as genetic disorders and other selected diseases occurring in children from birth through 24 months of age. About 10,000 Michigan children are born annually with birth defects or other reportable conditions. The MBDR currently contains 286,000 reports on approximately 143,000 children. An epidemiologist analyzes registry data and conducts special studies to better understand the impact of birth defects on public health.

### Prevention

Prevention includes identifying ways to reduce the risk of certain birth defects and educating communities and health professionals about prevention strategies including the promotion of daily adequate folic acid by all women of childbearing age to reduce the risk of neural tube defects. Other birth defects that can be prevented are caused by certain maternal illnesses, infections, or exposures such as alcohol. MDCH collaborates with many partners to address prevention, including the Michigan Chapter of the March of Dimes, statewide reproductive genetic centers, and the National Birth Defects Prevention Network (NBDPN). Key prevention activities in Michigan include:

- ✓ An ongoing folic acid educational campaign;
- ✓ Promotion of prevention strategies during national Birth Defects Prevention Month;
- ✓ Dissemination of informational materials including a free pamphlet, *Preventing Birth Defects—Important Information for Michigan Families*; and
- ✓ Outreach to special populations and high risk groups across the state.

### Follow-up

The birth defects follow-up component includes identifying the special needs of children with birth defects, and ensuring families are connected with available resources and support systems. Providing timely information to families while preserving the privacy of birth defects data is an important priority. During 2001-03, registry staff conducted a study in twenty Michigan hospitals to help identify the most useful and sensitive approach to providing follow-up based on gaps in existing referral systems, and have compiled the best practices that were found. The program also maintains a genetic support group directory located at [www.MiGeneticsConnection.org](http://www.MiGeneticsConnection.org) and distributes a pamphlet, *Resources for Families of Infants and Toddlers with Special Health Needs* at no cost to hospitals, health professionals and families. Follow-up on infants with neural tube defects began in 2004 and a parent handbook is being developed.

## The Michigan Birth Defects Registry (MBDR)

*“Each diagnosed incidence of a birth defect, including a congenital or structural malformation, or a biochemical or genetic disease, and any information relevant to incidents of birth defects shall be reported to the department. The department shall maintain comprehensive statewide records of all information reported to the birth defects registry.”*

-- Public Act 48 of 1987

The **purpose** of the MBDR is to:

- Collect statistical data on the incidence of birth defects in Michigan
- Conduct birth defects surveillance and epidemiologic studies on the causes of birth defects
- Provide data for birth defect prevention and intervention efforts, program planning and evaluation
- Assure that children with birth defects and their families receive appropriate support services.

Examples of uses for MBDR data include monitoring the rate and types of birth defects in specific geographic areas, planning and evaluating service delivery to children with special needs, targeting birth defects prevention activities, and conducting scientific research on the etiology of birth defects

### Reportable Conditions

The diagnoses reportable to MBDR include all congenital anomalies of consequence, genetic disorders presenting at birth or in early childhood, and selected maternal exposures to infectious diseases and other teratogenic agents such as alcohol. A manual that includes a list of reportable ICD-9 codes, enabling legislation and reporting instructions is provided to hospitals, cytogenetic laboratories and other reporting facilities. A list of reportable ICD-9 codes by diagnostic category is included as Appendix C.

The MBDR collects information on children from birth to two years of age who have a specified adverse outcome and were born in Michigan or were diagnosed or treated for the condition in Michigan. Adverse outcomes include congenital anomalies, inborn errors of metabolism, endocrine disorders, or hereditary blood, eye, nervous system or muscle disorders. Congenital exposure to infections, controlled substances or toxic substances are also reportable. Since June 1, 2003 fetal deaths with any of these conditions are also reportable. Previously, only live born children were included in the registry.

### Reporting Methods

Since the MBDR relies on data collected through passive case ascertainment, staff members strive to assist facilities in developing a reporting method best suited to their needs. Methods for reporting cases to the registry include:

- Paper Abstract- This method uses a standardized form in paper abstract for hospital admissions and cytogenetic laboratory results. (Appendices D and E)

- Electronic Submission- This method uses facility discharge data to create an electronic record of children admitted with reportable conditions.
- EBC, Electronic Birth Certificate- This method utilizes Genesis, the software commonly used to create electronic birth records for children born at a facility.

Voluntary reporting by outpatient pediatric genetic clinics was initiated in January, 2001. In addition, a voluntary prenatal ascertainment project to collect anonymous data from reproductive genetics clinics has been underway since early in 2001. Together these initiatives have expanded case ascertainment by contributing approximately 1,500 additional cases of birth defects to the MBDR that would have otherwise gone undetected.

Roughly 85 percent of all reports are received in electronic form, with about half of those being received through EBC and half as hospital-specific data files. Report processing procedures include de-duplication and consolidation of case reports, report review and query, coding and editing of reported information and linking the case information to Michigan birth and death files. Data from all three sources are used to develop a complete record on each case. Condition coding is accomplished using the current year version of the Ninth Revision of the International Classification of Diseases: Clinical Modification.

As an important public health indicator, birth defects reporting is mandated by state law and parental consent is not required before a report is filed. However, both law and rule establish that these data are confidential. Privacy and security considerations are integral to all procedural steps to assure confidentiality of information. Access to MBDR data is limited to essential registry personnel and other departmental staff whose programmatic use of the information has been approved by the Department director. Rules governing the MBDR specify the particular conditions and approval processes under which this information may be released.

### **Quality Assurance**

Concurrent internal monitoring assures that incoming reports are screened for missing and invalid information as they are being processed into the registry. MBDR staff compare demographic information on birth defects reports with that in birth and death records. They may contact data submitters at reporting facilities to find necessary information to correct and complete all data before they are linked with birth and death files. A tracking tool has been developed to accurately document the movement of birth defects data from the time it is received to the completion of processing.

Facility monitoring activities include selecting target facilities based on patterns of birth defects reporting. Initially, under-reporting is identified based on the expectation of seven percent of a facility's live births contributing cases of birth defects. The relationship between counties of residence and admitting facilities is reviewed. This helps to determine patterns of referral. Priority is given to those facilities which admit patients from a wider geographical area. Case finding is then conducted using discharge data provided to the department by the Michigan Health and Hospital Association. A target list of facilities that have demonstrated a poor history of reporting is developed. Backlog cases are ascertained and added to the registry, and education and support is provided to bring the facilities back to legislatively-mandated standards.

Retrospective facility audits are conducted to assess statewide performance in the reporting of birth defects and to identify opportunities for improvement. Thus, it is necessary to obtain a baseline picture of data quality and completeness at the facility level. An example below illustrates a representative cross-section of facilities from each of the four facility types that have been selected for site visits. Four facility types are represented in this audit:

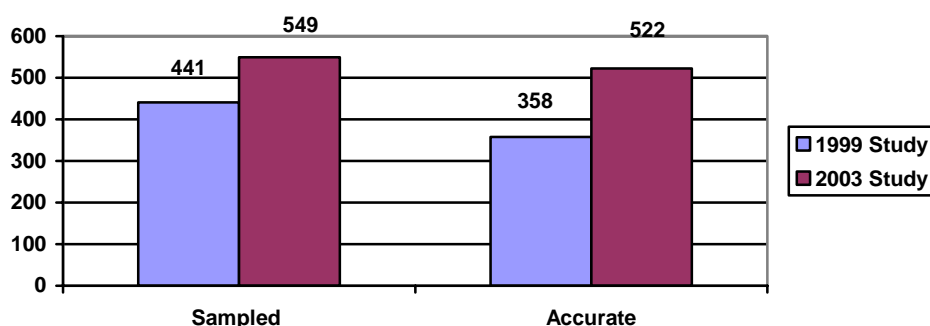
- minor obstetrical centers—4 facilities
- major obstetrical centers—2 facilities
- hospitals with regional neonatal intensive care units—2 facilities
- major referral center—1 facility

Health record audits were conducted at nine facilities in 1999. Repeat health record audits were conducted at nine additional facilities in 2003. Health records are reviewed at the facility to determine if the report submitted to the Birth Defects Registry is consistent with the information contained in the health record.

In the graph below (Figure 1), we can see that in the 1999 audit, 81.1% of the reported cases reviewed had information in the health record consistent with the information submitted to the registry. Improvement in accuracy was evident in the 2003 study, with an accuracy rate of 95.0% for the cases reviewed.

As a result of the first audit, reporting facilities received training and support targeted to their specific needs. An improvement in the quality of reports being submitted to the registry was recognized during the repeat facility audit conducted in 2003.

Figure 1  
Comparison of information accuracy between 1999 and 2003 studies



Discrepancies are broken down into two categories:

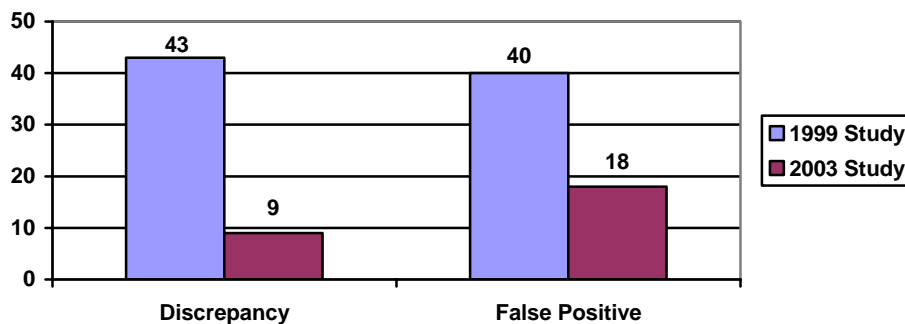
- Demographic discrepancies, where there is missing or inaccurate personal and contact information on a child or his/her mother
- Discrepancies involving inaccurate reporting of medical conditions to the Registry

Another important quality issue to consider when performing an audit is the occurrence of **false positive** cases. Two distinct types of false positive cases exist:

- No documentation in the health record exists to support that there was any abnormality; or
- Documentation in the health record suggests that there may be an abnormality, and follow-up tests or studies were ordered before discharge to rule out that condition. A report is sometimes submitted to the Registry before test results or consultation documentation can be added to the health record to document that there is no reportable condition.

In the graph below (Figure 2), we see that in the 1999 study, the discrepancies found were at 9.75% of cases reviewed, and false positives were at 9.07%. That number decreased in the 2003 study, with 1.63% of cases reviewed having discrepancies, and 3.27% being false positive cases.

Figure 2  
Comparison of information discrepancies/false positive cases  
between 1999 and 2003 studies



## Current Program Status

As a result of continuous CDC Cooperative Agreement funding since 1999, the MDCH Birth Defects Program has created the basic infrastructure for birth defects surveillance and initiated certain activities related to use of data for prevention and intervention purposes. Key staff members have been hired and are in place. A quality assurance program was initiated and the timeliness of processing incoming data reports was greatly improved. Data linkages with other programs were piloted at MDCH. An intradepartmental *Birth Defects Surveillance Steering Committee* was established to promote collaboration and monitor project activities, and continues to meet three times a year. Existing partnerships were strengthened and new partnerships forged with relevant organizations and programs such as the Michigan Chapter of the March of Dimes, Healthy Mothers Healthy Babies Coalition, *Early On*®, Children's Special Health Care Services (CSHCS), the state Fetal and Infant Mortality Review (FIMR) team, the Fetal Alcohol Syndrome (FAS) Program, local interagency coordinating councils, and others. A *Birth Defects Prevention and Monitoring Advisory Committee* was also established to advise the department and promote community-based educational outreach through local partners. Input from stakeholders in 1999 led to development of a plan, *Birth Defects in Michigan: An Approach to Prevention and Intervention*, that was used to guide original efforts. Subsequently, birth defects were addressed as part of a statewide genetics needs assessment and planning process, which resulted in a five-year state genetics plan, *Genetics Through The Life Cycle: Improving Health and Preventing Disease*, that now serves as a guiding framework for programmatic activities. The full plan can be viewed at [www.MiGeneticsConnection.org](http://www.MiGeneticsConnection.org).

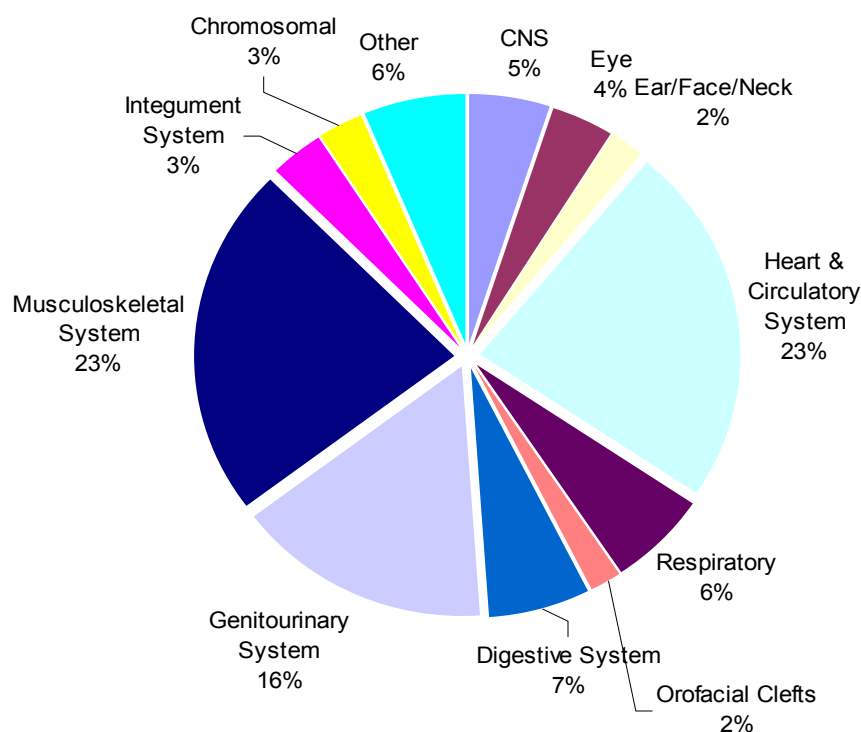


## *Selected Birth Defects Counts and Rates, 1992—2002*

Since its implementation in 1992, the MBDR has served as a vital source of information about birth defects, and summary data tables are included in Appendix F. The overall prevalence rate of birth defects has been steadily increasing from 726.8/10,000 in 1992 to 810.2/10,000 in 2002 with an average of 738.8/10,000 in this eleven-year time frame. An increase in prevalence rates was also observed in the three organ systems affected by the highest number of birth defects: heart and circulatory (129.8/10,000 in 1992 to 166.8/10,000 in 2002), musculoskeletal (147.7/10,000 in 1992 to 162.4/10,000 in 2002), and genitourinary (101.2/10,000 in 1992 to 113.8/10,000 in 2002) which may be attributed to better surveillance procedures and reporting. In 2002, the majority of birth defects cases fell into five diagnostic categories: heart and circulatory system (23.4%), musculoskeletal system (22.8%), genital and urinary system (16.0%), digestive system (6.5%), and respiratory system (6.0%). The remaining seven systems had five percent or fewer of all birth defect cases (Figure 3).

This section of the report will focus on four categories of birth defects, discussed in order of the extent to which prevention strategies are available to reduce the risk of occurrence. The conditions include: **1) neural tube defects (NTD)**; **2) orofacial clefts**; **3) Down syndrome**; and **4) congenital heart defects**.

Figure 3: All Michigan birth defects in 2002



The following tables summarize the overall prevalence rates for each congenital anomaly between 1992-2002. Heart defects have the highest prevalence rate at 119.7 per 10,000 live births, followed by orofacial clefts at 11.8 cases per 10,000 live births. The prevalence rates for neural tube defects and Down syndrome are 6.1 per 10,000 live births and 7.2 per 10,000 live births, respectfully. Appendix G provides mapping of these four conditions by county.

**Table 1:** Prevalence of selected birth defects in Michigan between 1992-2002. The order is based on current prevention strategies.

<b>Congenital Anomaly (ICD9 Code)</b>	<b>Rate<sup>1,2</sup></b>
Neural Tube Defects (740-742)	6.1
Spina Bifida (741.0, 741.9, w/o 740.0 or 740.1)	4.1
Anencephaly (740.0,740.1)	1.0
Encephalocele (742.0)	1.0
Orofacial Clefts (749)	11.8
Cleft Palate (749.00 - 749.04 w/o Cleft Lip 749.1 or 749.2)	4.8
Cleft Lip/Palate (749.1, 749.2)	6.9
Down Syndrome (758.0)	7.2
Heart Defects (745-746)	119.7
Ventricular Septal Defect (745.4)	28.4
Atrial Septal Defect (745.5)	33.2
Patent Ductus Arteriosis (747.0)	39.5
Pulmonary Artery Anomalies (747.3)	10.5

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

## Neural Tube Defects (NTD)

NTD are serious and often lethal birth defects of the brain and spine that occur during the first 28 days after conception when the neural tube is closing. *Anencephaly* is a fatal anomaly in which the neural tube fails to close. The brain does not develop properly or may be entirely absent. *Encephalocele* results from an opening in the skull associated with a skin covered sac-like structure containing central nervous system tissue or spinal fluid. It is usually fatal but babies who do survive typically have severe mental impairment. *Spina bifida* is the more common form of NTD in which the lower end of the neural tube fails to close, resulting in problems with development of the vertebrae and spinal cord. Babies with spina bifida require surgery soon after birth to prevent additional spinal cord damage and lower the risk of infection. Function is impaired below the level of the spinal lesion and sequelae may include impaired sensation, paralysis, and loss of bladder and bowel control. Long-term mobility is frequently a problem but difficult to predict. Some children with spina bifida may be able to walk without any help while others may need leg braces, crutches, or a wheelchair. Hydrocephalus is also common in children with spina bifida, and may require surgical placement of a shunt to reduce pressure on

the brain from excess spinal fluid. In addition to lifelong physical disabilities, children with spina bifida are at increased risk for learning disabilities.

Between 1992-2002, neural tube defects have a higher prevalence rate among women who give birth at the extremes of age (younger and older women). In Michigan, spina bifida has a higher rate among women who give birth over age 35, while younger women have a higher rate of anencephaly and encephalocele (Table 2). Overall, the prevalence rates for neural tube defects appear to be similar among all of the races (though “other” has a slightly higher rate) and both males and females have similar prevalence rates of neural tube defects (Tables 3 and 4).

The rate of NTD appears to be increasing since approximately 1998 (Figure 4) , which may be due to better surveillance and reporting of neural tube defects.

**Table 2:** Prevalence rate of neural tube defects stratified by mother's age

<b>Congenital Anomaly</b>	<b>Prevalence<sup>1,2</sup></b>				
	<b>&lt;20</b>	<b>20-24</b>	<b>25-29</b>	<b>30-34</b>	<b>35+</b>
Neural Tube Defects	6.6	6.3	6.0	5.2	6.6
Spina Bifida	4.0	4.1	4.3	3.6	4.8
Anencephaly	1.1	1.0	1.0	0.7	0.8
Encephalocele	1.4	1.1	0.8	0.9	1.0

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

**Table 3:** Prevalence rate of neural tube defects stratified by mother's race

Congenital Anomaly	Prevalence <sup>1,2</sup>			
	Whites	Blacks	Other <sup>3</sup>	Total
Neural Tube Defects	6.1	5.9	7.3	6.1
Spina Bifida	4.2	3.7	3.7	4.1
Anencephaly	1.0	0.7	2.9	1.0
Encephalocele	0.9	1.6	0.6	**

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

<sup>3</sup>Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

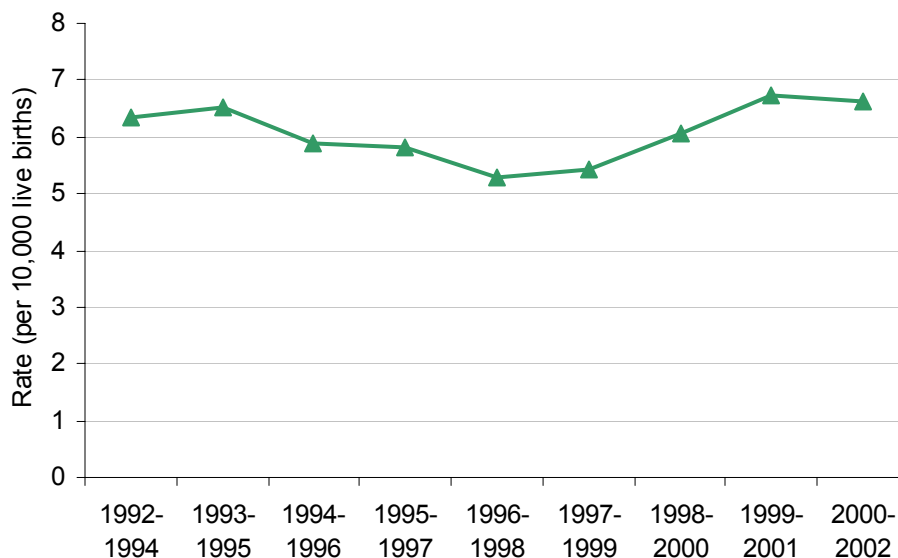
\*\* Fewer than 5 cases

**Table 4:** Prevalence rate of neural tube defects stratified by sex of infant

Congenital Anomaly	Prevalence <sup>1,2</sup>	
	Male	Female
Neural Tube Defects	5.9	6.2
Spina Bifida	4.1	4.1
Anencephaly	0.9	1.0
Encephalocele	1.1	1.1

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

**Figure 4:** Three year moving average of NTD between 1992-2002

## Orofacial Clefts

Orofacial clefts are a separation or split in part of the face that should normally be closed or joined together. Clefts can occur in the developing lip, as well as in the hard and soft palates of the mouth. Two major categories of orofacial clefts are cleft lip with or without cleft palate, and isolated cleft palate. Orofacial clefts occur very early in development—by 5-6 weeks after conception for clefts of the lip and by 10 weeks for palate malformations. A cleft may affect only one side of the lip and/or palate (unilateral) or both (bilateral). It may also affect the way the nose is formed and/or extend into the gum or upper jawbone. Babies with an orofacial cleft usually do not have other health problems unless the cleft is part of a genetic syndrome associated with other birth defects. Children with orofacial clefts usually undergo one or more surgical repairs early in life and may later need orthodontic care and speech therapy. They may also require special feeding techniques, and have a greater risk of ear infections. Both genetic and environmental factors are thought to play a role in the etiology of clefting, and recent studies by the CDC indicate that multivitamin use may reduce the risk of some facial clefts.<sup>9</sup>

**Table 5:** Prevalence rate of orofacial clefts stratified by mother's age

Congenital Anomaly	Prevalence <sup>1,2</sup>				
	<20	20-24	25-29	30-34	35+
Orofacial Clefts	12.8	12.7	11.4	10.7	11.6
Cleft Palate	5.3	4.8	5.2	4.4	4.5
Cleft Lip/Palate	7.6	7.9	6.2	6.3	7.2

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

**Table 6:** Prevalence rate of orofacial clefts stratified by mother's race

Congenital Anomaly	Prevalence <sup>1,2</sup>			
	Whites	Blacks	Other <sup>3</sup>	Total
Orofacial Clefts	12.9	6.8	8.9	11.6
Cleft Palate	5.3	3.0	3.5	4.8
Cleft Lip/Palate	7.6	3.8	5.4	6.8

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

<sup>3</sup>Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

**Table 7:** Prevalence rate of orofacial clefts stratified by sex of infant

Congenital Anomaly	Prevalence <sup>1,2</sup>	
	Male	Female
Orofacial Clefts	13.2	10.2
Cleft Palate	7.4	4.9
Cleft Lip/Palate	8.5	5.2

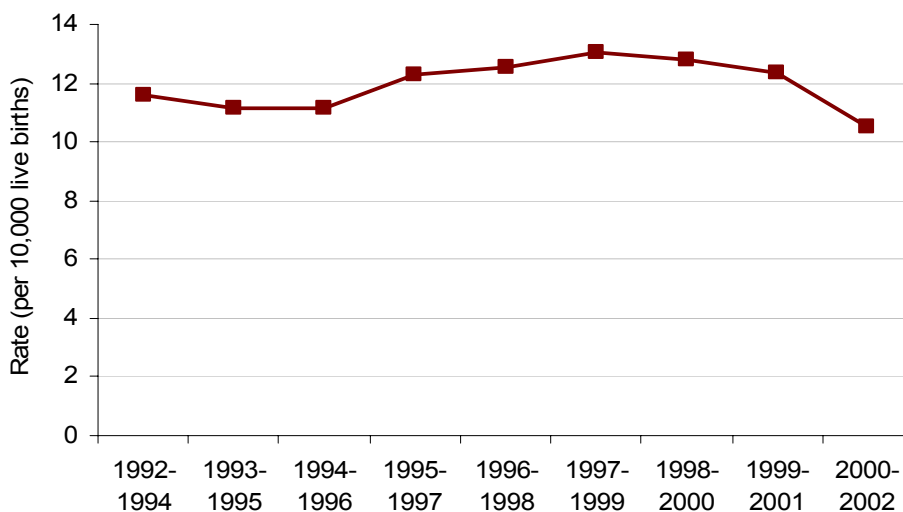
<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

Orofacial clefts have a slightly higher prevalence rate in women in their teens and early twenties (Table 5). In addition, orofacial clefts have the highest rate at 12.9 per 10,000 live births in whites and lowest at 6.8 per 10,000 live births in blacks (Table 6). Male infants have a higher rate of all orofacial clefts (Table 7).

The three-year moving average for orofacial clefts was increasing between 1994-1998. However, the prevalence rate has been declining for the past few years.

**Figure 5:** Three year moving average of orofacial clefts between 1992-2002



## Down Syndrome

Down syndrome is a lifelong condition caused by the presence of an extra copy of the twenty-first chromosome (trisomy 21). It is the most common chromosome abnormality occurring in liveborn infants, and is associated with varying degrees of mental retardation. About 50% of children with Down syndrome also have a congenital heart defect. Other characteristics may include a variety of physical signs such as particular facial features, digestive system problems, increased risk of infections as well as increased risk of hearing and vision problems. Although all the risk factors for Down syndrome are not known, the most common risk factor is maternal age 35 or older, which is also demonstrated by the MBDR data.

**Table 8:** Prevalence rate of Down syndrome stratified by mother's age

	Prevalence <sup>1,2</sup>				
<b>Congenital Anomaly</b>	<b>&lt;20</b>	<b>20-24</b>	<b>25-29</b>	<b>30-34</b>	<b>35+</b>
Down Syndrome	4.6	4.4	4.4	6.9	22.9

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

**Table 9:** Prevalence rate of Down syndrome stratified by mother's race

	Prevalence <sup>1,2</sup>			
<b>Congenital Anomaly</b>	<b>Whites</b>	<b>Blacks</b>	<b>Other<sup>3</sup></b>	<b>Total</b>
Down Syndrome	7.5	5.9	4.2	7.1

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

<sup>3</sup>Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

**Table 10:** Prevalence rate of Down Syndrome stratified by infant's sex

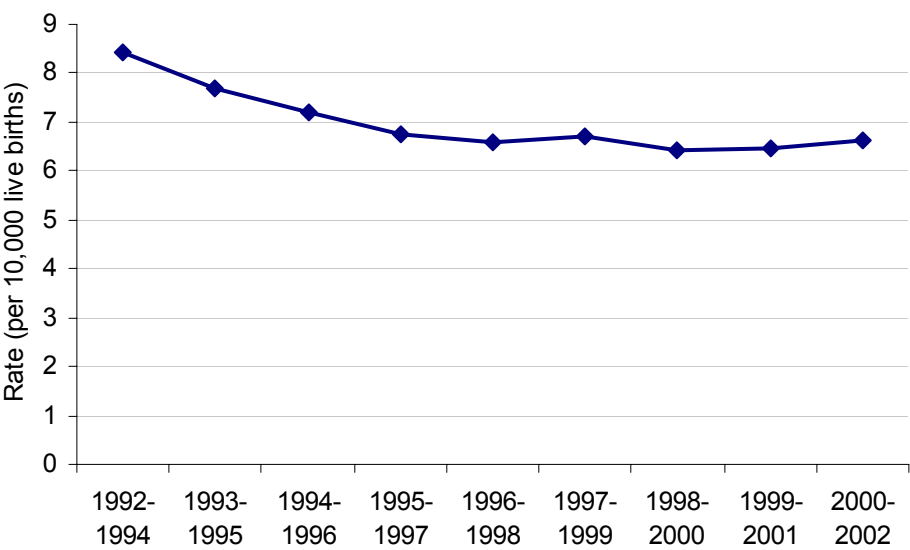
	Prevalence <sup>1,2</sup>	
<b>Congenital Anomaly</b>	<b>Male</b>	<b>Female</b>
Down Syndrome	7.7	6.5

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

As expected, between 1992-2002 the prevalence rate of Down syndrome increases as maternal age increases, with the highest prevalence in women over 35 (Table 8). In addition, white women had a higher prevalence of having a baby with Down syndrome (Table 9). Down syndrome had a slightly higher prevalence at 7.7 cases per 10,000 live births in male infants (Table 10). Figure 6 illustrates the three-year moving average rates between 1996-2002. The rates for Down syndrome appear to be unchanging or in a slight decline.

Figure 6: Three year moving average of Down syndrome between 1992-2002



## Congenital Heart (Cardiac) Defects

Cardiac defects are among the most commonly occurring congenital anomalies and originate during the early days of embryonic development. There are many different types of congenital heart defects. Some infants are born with only one type, while others have complex problems involving more than one type of heart defect. The most common types are ventricular septal defect (VSD) and atrial septal defect (ASD), in which a hole in the wall (septum) separating the heart chambers interrupts the flow of blood to the body. Congenital heart defects can range from minor conditions that may go undiagnosed for many years to severe malformations that cause death soon after birth. The need for surgery or other treatments depends on the specific type of malformation. While most children with a heart defect do not have additional health problems, about 10% may have a genetic syndrome as the etiology. Most of the time a specific cause cannot be pinpointed, but other known risk factors include environmental factors such as viral infections, certain medications, maternal diabetes, and alcohol consumption during pregnancy. Congenital heart defects are the leading cause of mortality for babies born with birth defects and affect both cardiac structure and function.

**Table 11:** Prevalence rate of congenital heart defects stratified by mother's age

	<b>Prevalence<sup>1,2</sup></b>				
<b>Congenital Anomaly</b>	<b>&lt;20</b>	<b>20-24</b>	<b>25-29</b>	<b>30-34</b>	<b>35+</b>
Heart Defects	113.7	110.1	118.0	121.0	146.0
Ventricular Septal Defect	24.5	23.4	28.9	30.5	37.1
Atrial Septal Defect	32.7	30.9	32.6	32.3	42.1
Pulmonary Ductus Arteriosis	36.7	35.4	40.4	40.1	47.6
Pulmonary Artery Anomalies	11.1	10.1	9.8	10.4	12.2

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

**Table 12:** Prevalence rate of congenital heart defects stratified by mother's race

	<b>Prevalence<sup>1,2</sup></b>			
<b>Congenital Anomaly</b>	<b>Whites</b>	<b>Blacks</b>	<b>Other<sup>3</sup></b>	<b>Total</b>
Heart Defects	115.1	140.1	71.9	118.4
Ventricular Septal Defect	29.8	21.4	18.9	27.9
Atrial Septal Defect	32.8	35.4	17.9	32.8
Pulmonary Ductus Arteriosis	37.5	49.3	16.8	39.0
Pulmonary Artery Anomalies	9.2	15.7	7.5	10.3

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

<sup>3</sup>Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

**Table 13:** Prevalence rate of congenital heart defects stratified by sex of infant

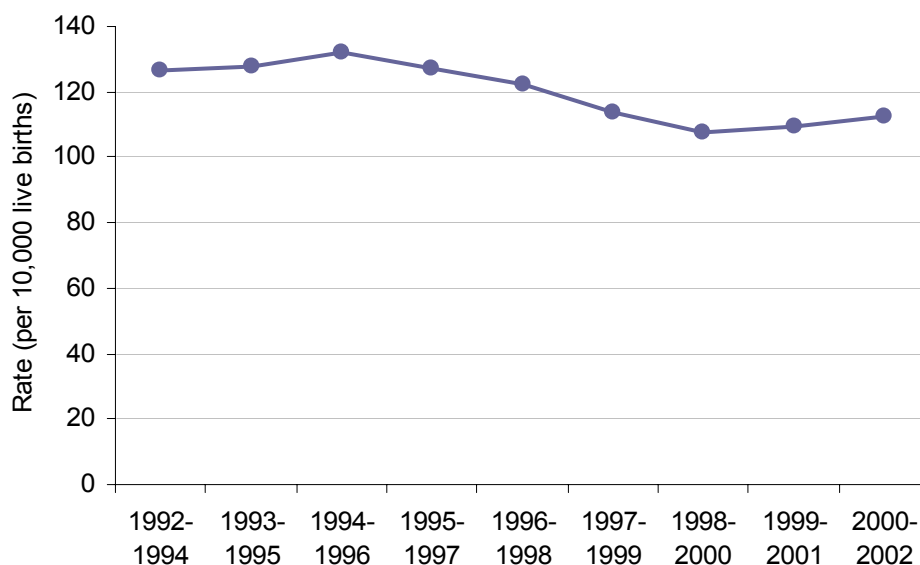
Congenital Anomaly	Prevalence <sup>1,2</sup>	
	Male	Female
Heart Defects	120.6	118.6
Ventricular Septal Defect	26.9	29.9
Atrial Septal Defect	32.3	34.1
Pulmonary Ductus Arteriosis	39.4	39.6
Pulmonary Artery Anomalies	10.2	10.8

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

As maternal age increases, the prevalence rate of congenital heart defects increases, with a peak rate in women aged 35 or older at 146.0 cases per 10,000 live births (Table 11). For heart defects overall, black women have the highest rate. However, when comparing rates by heart defect type, white women have the highest prevalence of ventricular septal defects, while black women have the highest rate of atrial septal defects, pulmonary ductus arteriosis, and pulmonary artery anomalies (Table 12). When comparing by infant's sex, heart defects appear to have a similar prevalence rate among both males and females (Table 13).

For birth defects of the heart, there was a steady decrease in rate between 1996-2000; however the prevalence rate has had a slight increase since 2000. It is also important to note the data from 2001 and 2002 are not complete, so estimates from these years may be inaccurate.

**Figure 7:** Three year moving average of congenital heart defects between 1992-2002

## *A Closer Look: NTD in Michigan*

Birth defects are the leading cause of infant mortality in the United States, affecting more than 120,000 newborns annually.<sup>10</sup> Of these, about 2,500 infants are born with the neural tube defects (NTD) spina bifida and anencephaly.<sup>11</sup> In addition, many other NTD-affected pregnancies are miscarried or terminated. All infants with anencephaly die shortly after birth, whereas the majority of babies born with spina bifida grow to adulthood, often with paralysis and varying degrees of bowel and bladder incontinence. The complications and secondary conditions associated with NTD place extensive economic, emotional, and physical burdens on affected children and their families, making this one of the most serious types of birth defects. Since 1992, about 80 Michigan live births annually continue to be affected by NTD including cases of anencephaly, encephalocele and spina bifida as reported to the MBDR.<sup>12</sup> The economic cost of providing specialty medical care to children with NTD enrolled in the Michigan Children's Special Health Care Services (CSHCS) Program amounted to more than \$3.7 million in fiscal year 2002.<sup>13</sup>

Additional evidence of the impact of NTDs upon all reproductive outcomes and not just those pregnancies resulting in liveborn infants is obtained from eight reproductive genetics clinics reporting to the MDCH Genetics Program. From 1999-2003, participating centers reported a total of **192 NTD-affected pregnancies**. Although some of these pregnancies were liveborn and reported to the MBDR, many ended prior to birth in miscarriage or termination. For this reason, the exact prevalence of NTD among all fetuses is difficult to ascertain. However, the total number of NTD-affected pregnancies is known to be considerably greater than the number of liveborn infants with NTD reported to the MBDR.

Fortunately, a strategy for *primary prevention* of neural tube defects has been identified. There is now indisputable scientific evidence that consumption of 400 mcg of folic acid before conception and during early pregnancy reduces the incidence of NTD by up to 70 percent.<sup>14,15</sup> In 1998, the Food and Drug Administration required the fortification of enriched breads, cereals, pasta, rice and other grain products with synthetic folic acid. However, it has been projected that the current level of folic acid food fortification in the United States will result in only approximately 25 percent of women of reproductive age consuming 400 micrograms of synthetic folic acid daily from all sources, including supplements.<sup>16</sup> Since fortification there has been a 26 percent decline in NTD live births reported nationally.<sup>17</sup> Unfortunately, Michigan has not experienced the same decline in NTD incidence that has been observed in other states.

*The vitamin folic acid is known to prevent up to 70% of neural tube birth defects*

### **Folic Acid Use in Michigan**

A 2004 March of Dimes evaluation of folic acid awareness and consumption among women of childbearing age conducted by the Gallup Organization showed that nationally, **only 40 percent** of women between the ages of 18-45 report consuming a daily multivitamin containing folic acid. The most current Michigan-specific data were reported in 2002. These data reveal that

approximately one-fifth (22%) of respondents in Michigan take a folic acid supplement or a vitamin containing folic acid on a daily basis. Folic acid supplement usage was lowest among minorities, younger (18-25) respondents, and respondents with less education.<sup>18</sup>

A 2004 Pregnancy Risk Assessment Monitoring System (PRAMS) study of women who had given birth in the second half of 2001 demonstrated that 55.3% were aware of folic acid and had received instruction about it from a health care professional; 23% were aware of it but had not received instructions from a health professional; 18.2% were neither aware nor had received any instruction; and 3.5% were instructed by a health care professional but had no prior awareness. More than half of the new mothers, 56.7%, indicated that they consumed no multivitamins in the month prior to pregnancy, while 27.9% reported daily consumption of a vitamin; 5.9% reported consumption 4-6 times per week; and 9.6% reported taking a multivitamin 1-3 times per week. The study concluded that the majority of women know about the sources and benefits of folic acid, but there is a disconnect in translating that awareness into action.<sup>19</sup>

## Summary NTD Data: Cases and Rates

In spite of continuing state and national efforts to increase folic acid consumption by women of childbearing age, neural tube defects continue to occur in Michigan at a significant rate. The tables and figures below provide a detailed analysis of NTD data obtained from the registry, including a breakdown by type of NTD.

**Table 14:** Seven year moving prevalence rate of neural tube defects from 1992-2002

	1992-1999	1993-2000	1994-2001	1995-2002
<b>Cases</b>				
Neural Tube Defects	641	653	646	640
Spina Bifida	435	440	448	443
Anencephaly	99	110	105	105
Encephalocele	107	103	93	92
<b>Rate <sup>1,2</sup></b>				
Neural Tube Defects	6.6	6.8	6.7	6.0
Spina Bifida	4.5	4.6	4.7	4.2
Anencephaly	1.1	1.2	1.0	1.0
Encephalocele	1.1	1.2	0.9	0.9

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

Between 1992-2002, the rate of neural tube birth defects appears to be unchanging, though a drop in rate is observed in the 1995-2002 period. However, it should be noted that the 2001 and 2002 registry information may be incomplete.

**Table 15:** Seven year moving prevalence rate of neural tube defects stratified by mother's age

	<b>Prevalence Rate<sup>1,2</sup></b>				
	<b>&lt;20</b>	<b>20-24</b>	<b>25-29</b>	<b>30-34</b>	<b>35+</b>
<i>1992-1999</i>					
Neural Tube Defects	6.8	6.2	6.1	4.8	6.6
Spina Bifida	4.3	4.1	4.2	3.4	4.4
Anencephaly	1.1	1.0	1.1	0.5	1.0
Encephalocele	1.4	1.0	0.8	0.9	1.2
<i>1993-2000</i>					
Neural Tube Defects	6.5	6.6	6.3	4.8	7.0
Spina Bifida	3.7	4.3	4.3	3.5	5.1
Anencephaly	1.3	1.2	1.2	0.6	1.0
Encephalocele	1.6	1.1	0.9	1.7	1.0
<i>1994-2001</i>					
Neural Tube Defects	6.3	6.2	6.3	4.8	7.7
Spina Bifida	3.5	4.3	4.4	3.6	5.8
Anencephaly	1.2	1.1	1.0	0.6	0.8
Encephalocele	1.5	0.8	0.9	0.6	0.8
<i>1995-2002</i>					
Neural Tube Defects	5.8	6.2	5.9	4.8	7.2
Spina Bifida	3.5	4.3	4.3	3.4	5.5
Anencephaly	1.0	1.1	0.9	0.7	0.9
Encephalocele	1.3	0.9	0.7	0.7	0.9

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

When stratified by age, spina bifida has the highest rate among older women (35+). The rates of anencephaly and encephalocele appear to be the highest among women less than 20 years of age (Table 15).

**Table 16:** Seven year moving prevalence rate of neural tube defects stratified by mother's race

	Prevalence Rate <sup>1,2</sup>			
	Whites	Blacks	Other <sup>3</sup>	Total
<i>1992-1999</i>				
Neural Tube Defects	6.0	5.7	4.8	5.9
Spina Bifida	4.2	3.5	3.2	4.8
Anencephaly	0.9	0.7	**	4.8
Encephalocele	0.9	1.5	**	1.0
<i>1993-2000</i>				
Neural Tube Defects	6.2	5.7	4.9	6.0
Spina Bifida	4.2	3.6	3.2	4.1
Anencephaly	1.1	0.7	1.5	1.0
Encephalocele	0.9	1.5	**	1.0
<i>1994-2001</i>				
Neural Tube Defects	6.1	5.5	7.1	6.0
Spina Bifida	4.3	3.7	4.3	4.2
Anencephaly	1.0	0.4	2.2	1.0
Encephalocele	0.8	1.3	**	1.0
<i>1995-2002</i>				
Neural Tube Defects	6.0	5.7	8.2	5.9
Spina Bifida	4.2	3.9	4.1	4.1
Anencephaly	1.0	0.4	3.5	1.0
Encephalocele	0.7	1.4	**	0.8

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

<sup>3</sup>Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

\*\* Fewer than 5 cases

The prevalence rate of neural tube defects appears to be similar among black and white women. The rates of NTDs in the “other” racial category appear to have an increasing rate, which may be attributed to the small sample size causing an artificial increase in rate.

**Table 17:** Seven year moving prevalence rate of neural tube defects stratified by infant sex

	<b>Cases</b>		<b>Prevalence Rate<sup>1,2</sup></b>	
	<b>Male</b>	<b>Female</b>	<b>Male</b>	<b>Female</b>
<i>1992-1999</i>				
Neural Tube Defects	318	320	5.7	6.0
Spina Bifida	218	214	3.9	4.0
Anencephaly	49	50	0.9	0.9
Encephalocele	51	56	0.9	1.1
<i>1993-2000</i>				
Neural Tube Defects	322	328	5.8	6.2
Spina Bifida	218	219	4.0	4.1
Anencephaly	54	56	1.0	1.1
Encephalocele	50	53	0.9	1.0
<i>1994-2001</i>				
Neural Tube Defects	348	365	5.7	6.3
Spina Bifida	216	228	3.9	4.3
Anencephaly	51	54	0.9	1.0
Encephalocele	47	46	0.9	0.9
<i>1995-2002</i>				
Neural Tube Defects	314	328	5.7	6.2
Spina Bifida	212	226	3.9	4.3
Anencephaly	50	55	0.9	1.1
Encephalocele	47	46	0.9	0.8

<sup>1</sup>Prevalence rates are based on resident occurrences. Data is accurate through January 2005.

<sup>2</sup>Prevalence rate expressed as cases per 10,000 live births

Overall, female infants appear to have a slightly higher prevalence rate of neural tube defects, with females having a prevalence rate of at least 6.0 per 10,000 live births, while male infants have a rate less than 6.0 per 10,000 live births.

Figures 8 and 9 depict the number of NTD cases by year as well as the rates. The number of cases of spina bifida appears to be increasing between 1999-2001 but drops in 2002 which may be due to incomplete reporting in 2002 (Figure 8). The rate of both NTD and spina bifida appears to increase between 1998 and 2001, then decrease from 2001 through 2002. However, this may be due to incomplete reporting in 2001 and 2002. The rates of anencephaly and encephalocele appear to have no significant decrease or increase in rate (Figure 9).

Figure 8: Number of neural tube defect cases by year

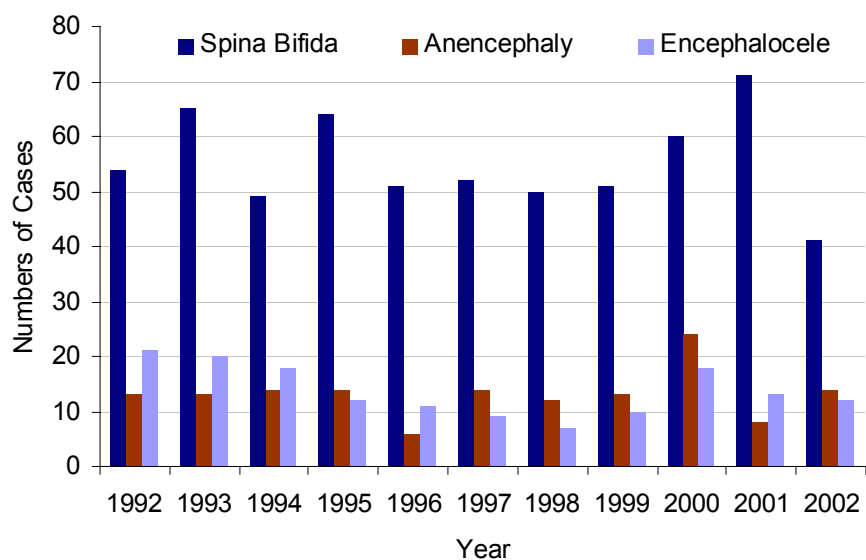
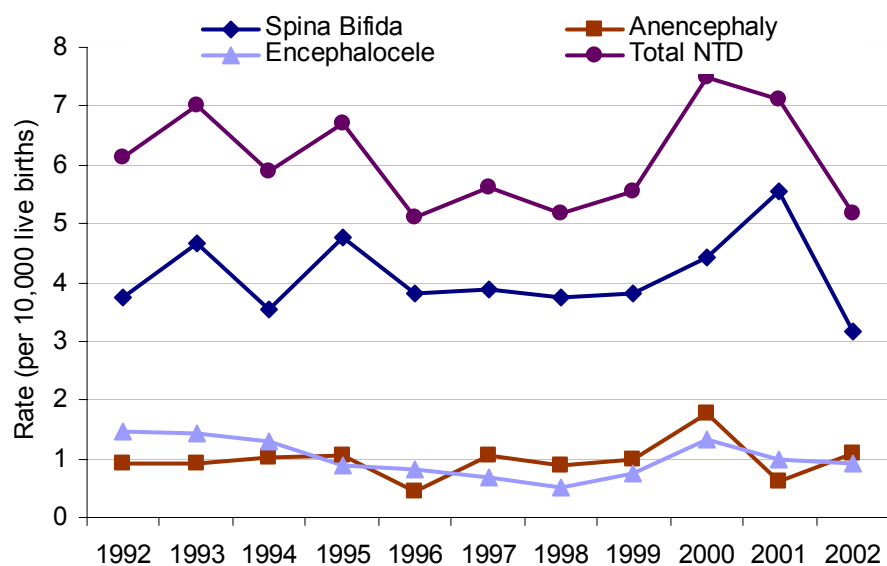


Figure 9: Rates of neural tube defects by year



## Focus on Prevention

While the etiology of many birth defects is presently unknown, certain preventive behaviors may reduce the risk for specific anomalies, especially if pregnancy is planned and preconceptional care is received. Because 40-50% of pregnancies in Michigan are unintended,<sup>20,21</sup> however, known strategies for reducing preventable birth defects are underutilized. Some of the prevention strategies include:

- Daily consumption of 400 micrograms of folic acid by ALL women of childbearing age before conception and during early pregnancy to reduce the risk of NTD and possibly other conditions such as Down syndrome, cardiovascular malformations and oral facial clefts,<sup>22,23</sup>
- Maternal immunity or reduced exposure to infectious diseases known to interfere with fetal development;
- Elimination of teratogenic agents such as alcohol, drugs, and certain medications during pregnancy; and
- Careful management of high risk mothers with medical conditions such as diabetes, phenylketonuria (PKU) and seizure disorders.

The need for continued efforts to reinforce public health prevention messages in Michigan is supported by the NTD statistics presented in the previous section of this report. A number of outreach activities are currently underway within MDCH and through the efforts of local health departments, private practices, and non-profit organizations. Since 1999, folic acid and other prevention outreach activities have been initiated including distribution of the pamphlet *Preventing Birth Defects—Important Information for Michigan Families*. Beginning in 2000, MDCH participates in the National Birth Defects Prevention Network (NBDPN) campaign to promote Birth Defects Prevention Month. During January the department distributes information packets on surveillance data, prevention strategies, and resources to a variety of target groups. In the past, recipients have included county and district health departments; Women, Infants, and Children (WIC) Nutrition Program coordinators; nursing schools; and reproductive genetics centers. Other examples of prevention activities are listed in Figure 10.

The department also assumed statewide leadership for a folic acid education campaign in 2001 when the March of Dimes transitioned its major focus to prematurity and pre-term birth.

**Figure 10.**  
**Examples of Folic Acid/Birth Defects Prevention Outreach Activities, 2000- 2004**

- Development and broadcast of radio PSA by state community health director
- Governor's executive declaration of Birth Defects Prevention Month
- Folic acid message on state employee paychecks
- Prevention information on website
- Folic acid article in school health newsletter sent to more than one million families
- Distribution of pamphlets, posters and videos at professional conferences
- Visits to myelomeningocele clinics
- Folic acid TV spot on NBC Detroit Affiliate
- "Nelda's Nutrition Nuggets" in grocery store circular
- Table displays at conferences such as WIC, Healthy Mothers Healthy Babies, Michigan State Medical Society, Michigan Dietetic Association and public events including Festival Latino
- Birth defects prevention page in "Watch Me Grow" calendar for families of infants and young children
- Folic acid/prevention Listserv to promote communication among community partners

To address concerns about the increased risk of *NTD recurrence* in families who already have an affected child, a follow-up project was initiated in 2004. After a baby with NTD is identified by the registry, the nurse coordinator sends a letter with resource information to the family. Contact is initiated only after the child's diagnosis is confirmed through the CSHCS database or by abstracting the medical record from the reporting facility. A second letter that includes NTD recurrence prevention information is mailed three to four months after the first contact with NTD recurrence prevention information with a questionnaire to assess knowledge of folic acid and the need for further assistance.

In addition to the focus on NTD, strategies for preventing other types of birth defects have been identified. A thorough review of all known causes of birth defects was conducted, including maternal medical conditions and infectious exposures. Registry staff are currently collaborating with other MDCH programs to address Fetal Alcohol Spectrum Disorder as well as maternal PKU and diabetes as risk factors for birth defects.

## *Mortality in Children with Birth Defects*

The mortality experienced by Michigan children with birth defects is appreciably higher than for children in general. Birth defects registry data indicate that the contribution of birth defects to infant and childhood mortality is more than twice that indicated by cause of death data alone. The relative risk of death for children with birth defects is roughly **seven times** that of other children. The elevated relative risk of death for children with birth defects is highest at ages 1 to 2. Children with birth defects constitute 7.1 percent of the children and 46 percent of all deaths at age one, with a relative risk of mortality that is 11 times the mortality rate of other children. Elevated mortality is experienced by registry children for all ages examined, including through the age of 10 years.



This picture of mortality in children with birth defects and the strong impact this has on overall Michigan infant and childhood mortality can be drawn using data from the MBDR. One of the objectives of the registry is to be able to monitor infant and childhood mortality among children reported to the Michigan Birth Defects Registry. In order to better understand the impact of birth defects, the mortality of children in the registry is routinely monitored using a passive system of birth death matching. This matching work is done annually for all children in the registry and includes all reportable cases born since 1992. This linkage process uses the Michigan death registry files and death reports from other states involving Michigan-born children. To examine the resulting data in a meaningful way, comparative data on the mortality of all Michigan children is also routinely developed. The result is a unique resource for studying the long-term effects of birth defects on infant and childhood health and survival.

Evaluating the mortality rate of children in the registry is an excellent measure of the impact of birth defects on infant and childhood health. These data can also be used to evaluate the risk of mortality for children with specific defects. The causes of death that represent the greatest mortality risk to children can also be evaluated. Finally, mortality rates and relative risk by age can be monitored using this information, along with trends in mortality over time.

Presently, the MBDR contains data on mortality in children through 10 years of age. The information includes the mortality experience of 108,992 children born with birth defects over the years 1992 through 2002 and for 1,366,298 Michigan resident/occurrent births over these same years for children without reported birth defects. A total of 14,708 deaths have occurred within both cohorts, with 5,253 deaths in children with birth defects and 9,455 deaths among those without.

Using these data, the number of deaths by age at death can be determined for children with birth defects, compared with deaths by age for all other children. This information, provided in Tables 18 and 19, indicates that the impact of birth defects on infant and childhood mortality is extensive.

Table 18: Deaths to MBDR Children by Birth Year and Age at Death  
Michigan Resident/Occurrent Births - 1992 through 2002  
Death Links for Completed Years through 2003 Deaths

Year of Birth	MBDR Births	Under 1 Year	1 to 2 Years	2 to 3 Years	3 to 4 Years	4 to 5 Years	5 to 6 Years	6 to 7 Years	7 to 8 Years	8 to 9 Years	9 to 10 Years	10 to 11 Years
All Years	108,992	4,443	316	178	92	69	39	41	34	26	10	5
1992	10,385	471	42	30	18	11	11	10	5	7	7	5
1993	10,202	443	43	21	15	12	3	10	9	10	3	-
1994	10,036	436	33	27	9	11	2	5	8	9	-	-
1995	8,831	372	27	11	9	9	9	9	12	-	-	-
1996	8,800	355	25	19	9	12	10	7	-	-	-	-
1997	8,822	399	24	23	12	9	4	-	-	-	-	-
1998	9,145	390	22	14	7	5	-	-	-	-	-	-
1999	10,003	390	38	19	13	-	-	-	-	-	-	-
2000	11,028	407	29	14	-	-	-	-	-	-	-	-
2001	11,375	392	33	-	-	-	-	-	-	-	-	-
2002	10,365	388	-	-	-	-	-	-	-	-	-	-
MBDR Children at Risk of Death by Age		108,992	94,572	83,306	72,550	65,757	54,139	45,749	37,345	28,938	19,416	9,773

Children at risk is defined as the number of children surviving to the beginning of an age group.

Table 19: Deaths to Non-MBDR Children by Birth Year and Age at Death  
Michigan Resident/Occurent Births - 1992 through 2002  
Death Links for Completed Years through 2003 Deaths

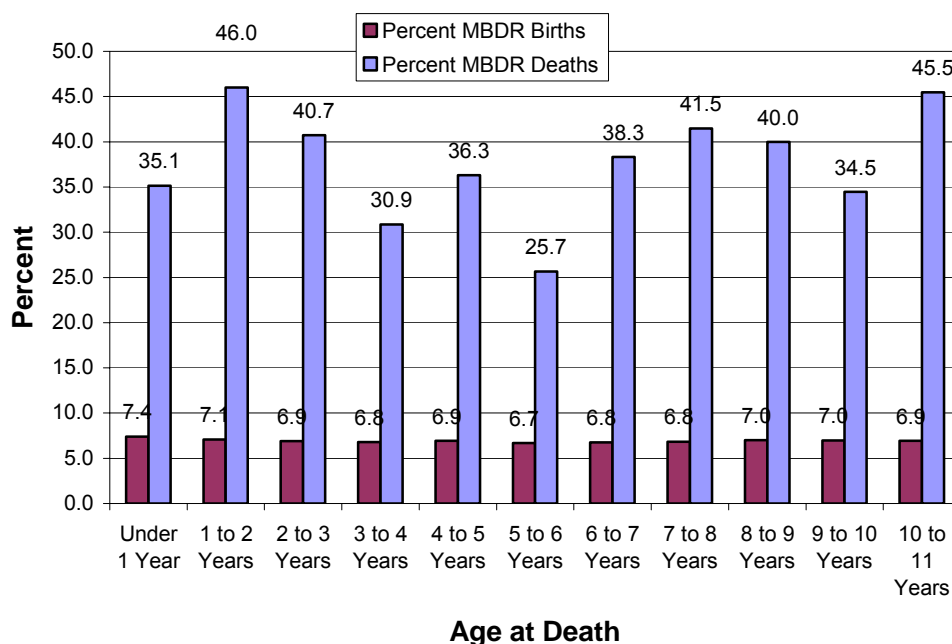
Year of Birth	Non-MBDR Births	Under 1 Year	1 to 2 Years	2 to 3 Years	3 to 4 Years	4 to 5 Years	5 to 6 Years	6 to 7 Years	7 to 8 Years	8 to 9 Years	9 to 10 Years	10 to 11 Years
All Years	1,366,298	8207	371	259	206	121	113	66	48	39	19	6
1992	132,495	1023	48	47	40	20	20	20	16	12	13	6
1993	128,933	848	42	30	28	20	34	5	19	19	6	-
1994	126,693	767	42	28	21	23	18	18	9	8	-	-
1995	124,464	737	38	38	35	16	13	14	4	-	-	-
1996	123,282	723	39	35	25	14	20	9	-	-	-	-
1997	123,549	706	43	37	24	18	8	-	-	-	-	-
1998	123,160	713	35	19	18	10	-	-	-	-	-	-
1999	122,202	684	35	17	15	-	-	-	-	-	-	-
2000	123,603	742	27	8	-	-	-	-	-	-	-	-
2001	120,348	681	22	-	-	-	-	-	-	-	-	-
2002	117,569	583	-	-	-	-	-	-	-	-	-	-

Non-MBDR Children at Risk of Death by Age	1,366,298	1,241,105	1,121,089	998,004	881,571	753,861	631,035	508,552	384,935	259,137	131,236
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Children at risk is defined as the number of children surviving to the beginning of an age group.

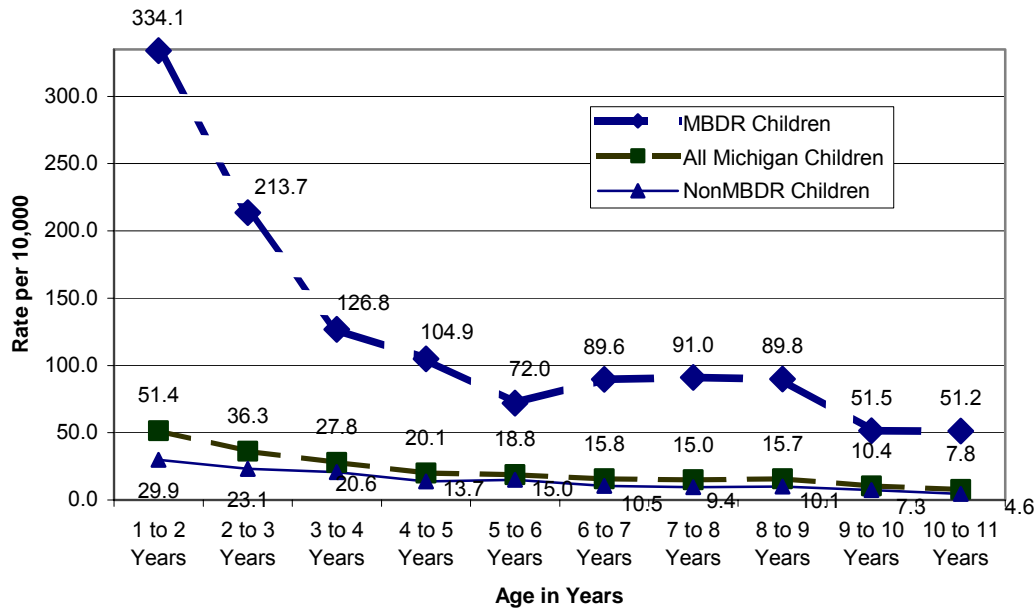
While children with birth defects comprise about seven percent of all Michigan children, the deaths to this group of children constitute 35.7 percent of all deaths to children from the birth years 1992 through 2002 and dying during the period 1992 through 2003. The percentage of all infant deaths during the time period was 35.1. For age one year, the percentage of all deaths that are to MBDR children reaches 46 percent. The percentage declines for two-year-olds and declines again for three-year-olds, staying relatively lower through age six. The percentage for five-year-olds, 25.7 percent, was the lowest percentage observed. After age five the proportion of deaths to MBDR children rises gradually through age 10. The proportion of MBDR births at risk and the proportion of deaths to MBDR children is displayed in Figure 11.

**Figure 11: MBDR Cases and Deaths as a Percent of All Cases/Deaths by Age at Death**  
**Michigan Resident/Occurent Cases**  
**Born between 1992 and 2002 and Dying by 2003**



The infant mortality rate for MBDR children born over the years 1992 through 2002 was 4076.4 per 100,000. Mortality rates declined to 334.1 for MBDR one-year-olds and continued dropping to age five when the observed rate was 72.0. These mortality rates are significantly higher than the mortality rates for non-MBDR children over the same time period. These data are presented in Tables 20 and 21. The tables include mortality rates by age and by birth year for the birth cohorts 1992 through 2002. Significantly higher mortality is consistently evident for children with birth defects across all ages and birth cohorts.

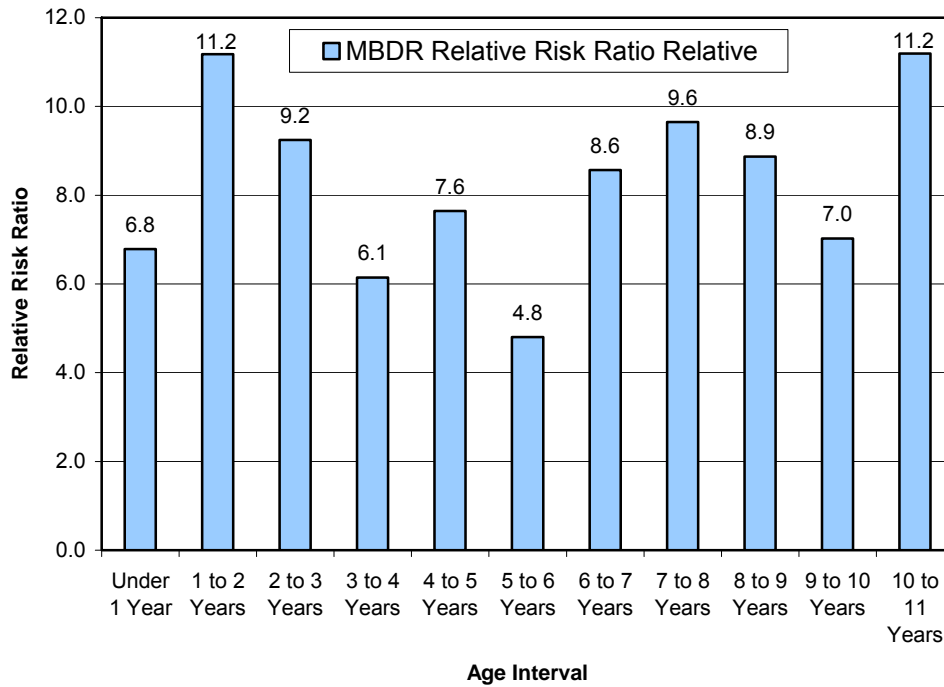
**Figure 12: Mortality Rates by Age and Presence of Birth Defects**  
Michigan Resident/Occurrent Births - 1992 through 2002  
Children Aged 1 through 10 years by Birth Defects Status



The mortality rates by age are displayed graphically for children aged 1 through 10 years in Figure 12. The higher mortality of children with birth defects is evidenced by the significantly higher mortality curve for these children compared to all Michigan children, and to children with no reported birth defect.

The relative mortality risk for MBDR infants is 6.8 times that of non-MBDR infants. The relative mortality risk for MBDR children is 11.2 for age one year, dropping to 4.8 by age five then tending to increase with increasing age through age 10. The relative risk of MBDR mortality by age is displayed in Figure 13.

**Figure 13: Relative Mortality Risk Ratio for MBDR Children by Age Interval**  
**MBDR Mortality Rate divided by Non-MBDR Mortality Rate by Age Interval**



**Programs to reduce infant and childhood mortality must include efforts to address the health problems of children with birth defects**

These data demonstrate the severe mortality experience of children with birth defects. The exaggerated proportion of deaths that are occurring to these children clearly indicate that programs to reduce infant and childhood mortality must include efforts to address issues that relate to the health problems of children with birth defects.

Table 20: Age-specific Mortality Rates for MBDR Cases by Year  
 MBDR Resident/Occurrent Births - 1992 through 2002  
 Death Links for Completed Years through 2003

Year of Birth	Under 1 Year	1 to 2 Years	2 to 3 Years	3 to 4 Years	4 to 5 Years	5 to 6 Years	6 to 7 Years	7 to 8 Years	8 to 9 Years	9 to 10 Years	10 to 11 Years
All Years	4076.4	334.1	213.7	126.8	104.9	72.0	89.6	91.0	89.8	51.5	51.2
1992	4535.4	423.6	303.9	182.9	112.0	112.1	102.0	51.1	71.5	71.6	51.2
1993	4342.3	440.6	216.1	154.7	124.0	**	103.5	93.2	103.7	**	-
1994	4344.4	343.8	282.2	94.3	115.4	**	52.5	84.1	94.7	-	-
1995	4212.4	319.2	130.5	106.9	107.0	107.1	107.2	143.1	-	-	-
1996	4034.1	296.0	225.7	107.1	143.0	119.3	83.6	-	-	-	-
1997	4522.8	284.9	273.8	143.3	107.6	**	-	-	-	-	-
1998	4264.6	251.3	160.3	80.3	57.4	-	-	-	-	-	-
1999	3898.8	395.3	198.4	136.0	-	-	-	-	-	-	-
2000	3690.6	273.0	132.2	-	-	-	-	-	-	-	-
2001	3446.2	300.5	-	-	-	-	-	-	-	-	-
2002	3743.4	-	-	-	-	-	-	-	-	-	-

Age-specific MBDR rate for study period	4076.4	334.1	213.7	126.8	104.9	72.0	89.6	91.0	89.8	51.5	51.2
Cumulative MBDR death rate through age group	4076.4	4410.6	4624.3	4751.1	4856.0	4928.0	5017.7	5108.7	5198.5	5250.0	5301.2

\*\* Too few observations to calculate rate  
 - Data not yet available  
 Rates are per 100,000

Table 21: Age-specific Mortality Rates for Non-MBDR Cases by Year  
Non-MBDR Resident/Occurrent Births - 1992 through 2002  
Death Links for Completed Years through 2003

Year of Birth	Under 1 Year	1 to 2 Years	2 to 3 Years	3 to 4 Years	4 to 5 Years	5 to 6 Years	6 to 7 Years	7 to 8 Years	8 to 9 Years	9 to 10 Years	10 to 11 Years
All Years	600.7	29.9	23.1	20.6	13.7	15.0	10.5	9.4	10.1	7.3	4.6
1992	772.1	36.5	35.8	30.4	15.2	15.2	15.2	12.2	9.1	9.9	4.6
1993	657.7	32.8	23.4	21.9	15.6	26.6	3.9	14.9	14.9	4.7	-
1994	605.4	33.4	22.2	16.7	18.3	14.3	14.3	7.2	6.4	-	-
1995	592.1	30.7	30.7	28.3	12.9	10.5	11.3	**	-	-	-
1996	586.5	31.8	28.6	20.4	11.4	16.3	7.4	-	-	-	-
1997	571.4	35.0	30.1	19.5	14.7	6.5	-	-	-	-	-
1998	578.9	28.6	15.5	14.7	8.2	-	-	-	-	-	-
1999	559.7	28.8	14.0	12.3	-	-	-	-	-	-	-
2000	600.3	22.0	6.5	-	-	-	-	-	-	-	-
2001	565.9	18.4	-	-	-	-	-	-	-	-	-
2002	495.9	-	-	-	-	-	-	-	-	-	-

Age-specific Non-MBDR rate for study period	600.7	29.9	23.1	20.6	13.7	15.0	10.5	9.4	10.1	7.3	4.6
Cumulative Non-MBDR death rate through age group	600.7	630.6	653.7	674.3	688.0	703.0	713.5	722.9	733.1	740.4	745.0

\*\* Too few observations to calculate rate  
- Data not yet available  
Rates are per 100,000

Table 22: Age-specific Mortality Rate Ratios for MBDR Children by Birth Year and Age at Death  
Michigan Resident/Occurrent Births - 1992 through 2002  
Death Links for Completed Years through 2003 Deaths

Year of Birth	Under 1 Year	1 to 2 Years	2 to 3 Years	3 to 4 Years	4 to 5 Years	5 to 6 Years	6 to 7 Years	7 to 8 Years	8 to 9 Years	9 to 10 Years	10 to 11 Years
All Years	6.8	11.2	9.2	6.1	7.6	4.8	8.6	9.6	8.9	7.0	11.2
1992	5.9	11.6	8.5	6.0	7.4	7.4	6.7	4.2	7.8	7.2	11.2
1993	6.6	13.4	9.2	7.1	7.9	**	26.5	6.3	7.0	**	-
1994	7.2	10.3	12.7	5.7	6.3	**	3.7	11.8	14.9	-	-
1995	7.1	10.4	4.2	3.8	8.3	10.2	9.5	**	-	-	-
1996	6.9	9.3	7.9	5.2	12.5	7.3	11.4	-	-	-	-
1997	7.9	8.1	9.1	7.3	7.3	**	-	-	-	-	-
1998	7.4	8.8	10.3	5.5	7.0	-	-	-	-	-	-
1999	7.0	13.7	14.2	11.0	-	-	-	-	-	-	-
2000	6.1	12.4	20.3	-	-	-	-	-	-	-	-
2001	6.1	16.3	-	-	-	-	-	-	-	-	-
2002	7.5	-	-	-	-	-	-	-	-	-	-

Age-specific rate ratios for study period	6.8	11.2	9.2	6.1	7.6	4.8	8.6	9.6	8.9	7.0	11.2
Cumulative mortality rate ratios through age 10	6.8	7.0	7.1	7.0	7.1	7.0	7.0	7.1	7.1	7.1	7.1

## *March of Dimes Partnership*

As a national advocacy organization focusing on the health of mothers and babies since 1958, the March of Dimes Birth Defects Foundation (MOD) has been a major force in raising awareness of birth defects prevention strategies and providing financial support for scientific research on causation and treatment. Other important objectives of the MOD include reducing infant mortality and low birth weight, removing barriers to prenatal care, and promoting public and professional education and advocacy. March of Dimes leadership has also played a key role in spearheading initiatives to bring birth defects to the attention of federal and state policy makers, and in lobbying for legislation to support surveillance programs.<sup>24</sup>

Birth Defects Program staff have a close working relationship with the March of Dimes, Michigan Chapter and have participated as members of the Program Services and Public Affairs Committees. An MOD grant in 2002-03 allowed MDCH to assume leadership of the statewide folic acid campaign, and MOD community award funding in 2005 will support distribution of multivitamins with folic acid to women in counties with the highest NTD rates. MDCH appreciates the support provided by the March of Dimes and looks forward to an ongoing partnership that continues to improve and enhance birth defects monitoring, prevention, and follow-up efforts statewide.



# Research Projects and Publications

## Poster Presentations

(in chronological order)

**Quality Assurance Methods for Field Audits**  
Lorrie Simmons, Dennis Dodson, Glenn Copeland  
NBDPN Annual Conference, 2001

**Coordination Between the Early Hearing Detection and Intervention Program (EHDI) and the Michigan Birth Defects Registry (MBDR)**  
Janice Bach, Glenn Copeland, Elise Dimon, Dennis Dodson, Lorrie Simmons  
NBDPN Annual Conference, 2002

**Birth Defects Rate Among Michigan Children Born to HIV Positive Mothers**  
Glenn Copeland, Nilsa Mack, James Kent, JoLynn Montgomery, Eve Mokotoff  
NBDPN Annual Conference, 2003

**The Risk of Mortality and Survival Trends for Children <7 Years of Age Born with Congenital Anomalies in Michigan, 1992-1998**  
Katherine Berger, Glenn Copeland, Bao-Ping Zhu  
NBDPN Annual Conference, 2003

**An Evaluation of the Leading Causes of Death and Relative Risk of Death by Underlying Cause of Death Grouping Among Infants and Children with Reportable Conditions**  
Glenn Copeland  
NBDPN Annual Conference, 2004

**Michigan Children with Birth Defects: The Role of Hospitals in Linking Families with Services**  
Jane Simmermon, Lorrie Simmons, Janice Bach, Glenn Copeland  
NBDPN Annual Conference, 2004

**A Different View of Birth Defects as a Cause of Mortality: Using Birth Defects Registry Data to Evaluate the Full Effect of Birth Defects on Infant and Childhood Mortality, to Examine the Relative Risk of Mortality and Determine the Cause of Death Distribution among Children with Birth Defects**  
Glenn Copeland  
NCBDDD Annual Conference, 2004

**Contribution of Preterm Births to Michigan's CSHCS Program Population**  
Violanda Grigorescu, Michael Paustian, Glenn Copeland  
MCH Epidemiology Annual Conference, 2004

**Monitoring Birth Defects Rates in a Cohort of Perinatally HIV-Exposed Infants**  
Glenn Copeland, Nilsa Mack, Yolanda Moore, Eve Mokotoff  
NBDPN Annual Conference, 2005

**Trends in Major Birth Defects in Michigan, 1992-2001**  
Rupali Patel, Violanda Grigorescu, Glenn Copeland, Jane Simmermon, Janice Bach  
NBDPN Annual Conference, 2005

## Articles (in alphabetical order by author)

Arole A, Pruder K, Reznar M, Eby E, Zhu B. **Folic acid awareness in Michigan, 1996-1999.** Obstet Gynecol. 2003 Nov; 102: 1046-1050.

Berger K, Copeland G, Zhu B. **The risk of mortality throughout early childhood for Michigan children born with congenital anomalies, 1992-1998.** Teratology Part A: 2003;67(9):656-661.

Berger K. **Congenital anomalies and childhood mortality in Michigan, 1992-1998.** Michigan Department of Community Health. Epi Insight. Lansing, MI: Bureau of Epidemiology, Michigan Department of Community Health, Winter, 2003.

Centers for Disease Control and Prevention. **Knowledge and use of folic acid among women of reproductive age-Michigan, 1998.** Reported by: M Reeves, A Rafferty, JC Simmermon, J Bach, and EIS Officer, CDC.MMWR. March 16, 2001; 50 (10):185-189.

Eby E, Zhu B, Bach J, Bouraoui Y, Miller K, Paterson D. **Folic Acid Awareness Among Michigan Mothers, 1996-1999.** Michigan Department of Community Health. MI PRAMS Delivery. Volume 1, Number 2. Lansing, MI: Division of Family and Community Health, Michigan Department of Community Health, April 2002.

Mercer N, Simmermon J, Bach J, Dickinson J, Kannan S. **Survey of dietetic and nursing health professionals in Michigan reveals a need for continuing education on the role of folic acid in preventing neural tube defects.** Manuscript in preparation, Spring, 2005.

Michigan Department of Community Health, Birth Defects Registry. **Selected birth defects statistics** published in Teratology: 2001 (vol 64), 2002 (vol 66), 2003 (vol 67) and 2004 (vol 70).

Simmermon J. **Preach against birth defects—promote folic acid.** Nursing Profile. January, 2002:34.

Simmermon J. **Birth defects monitoring, prevention, and follow-up in Michigan.** Michigan Department of Community Health. Epi Insight. Lansing, MI: Bureau of Epidemiology,

Michigan Department of Community Health, Winter, 2004.

Simmermon J. **Birth defects monitoring, prevention, and follow-up in Michigan.** Southeastern Michigan Association of Neonatal Nurses. SMANN News. 2004; 14:10-11.

Simmermon J. **Reducing the risk of birth defects: a daily multivitamin is more important than you think!** Metro Baby. Fall/Winter, 2004:4.

Simmermon J. **Birth defects monitoring, prevention, and follow-up in Michigan.** Southeastern Michigan Association of Neonatal Nurses. SMANN News. 2005; 15:10-11.

# State and National Resources

*After the birth or adoption of a child with special needs, parents sometimes have questions. There are many programs in Michigan available free of charge. Many programs are run by parents who want to share information.*

## Family Support

**The Birth Defects Follow-up Program** at the Michigan Department of Community Health (MDCH) can help with referrals for support and services. The program provides resource information for families and health care providers. To speak with the follow-up coordinator or receive materials, call toll-free (866) 852-1247, e-mail [BDRFollowup@michigan.gov](mailto:BDRFollowup@michigan.gov) or visit [www.migeneticsconnection.org](http://www.migeneticsconnection.org)

Families of children with all types of special needs share information and support in the **Family Support Network of Michigan**. To contact the network, call the Children's Special Health Care Services (CSHCS) Family Phone Line at (800) 359-3722.

**Bridges4Kids** is a parent organization providing a comprehensive system of information and referral for parents of all children from birth to adult life with a special focus on those who have disabilities, special needs, or who are at-risk. For more information visit [www.bridges4kids.org](http://www.bridges4kids.org) or call toll-free (877) 553-5437.

**Family Support Services** are offered through local community mental health agencies. Case management can help arrange services. Behavior intervention, family skills development, and respite care services are also available. Through respite care, families get a short break from caring for a child with special needs. To apply for family support services, call your local **Community Mental Health Services Program** listed in the business section or yellow pages. If you need help finding the telephone number, call the Michigan Association of Community Mental Health Boards at (517) 374-6848.

**Parent HELpline** is a service of Gateway Community Services, funded by the Department of Human Services. It is available to anyone who needs help right away. The HELpline is open 24 hours a day, seven days a week. Trained counselors provide crisis counseling, support and information. The free, confidential number is (800) 942-HELP.

The **Parent Empowerment Project** serves families caring for children who are medically fragile or technology-dependent. Parent advocates can provide

information and informal support. A related project, **Resources Unlimited Dedicated to You (RUDY)** provides information on medical equipment, resources and a supply exchange for caregivers of children with special needs. Call (800) 262-0650, or see [www.for-rudy.com](http://www.for-rudy.com)

**Project PERFORM** is a support and resource center for families of children with special needs. The project provides information folders, a lending library, and one-on-one support. Parents oversee the center and answer calls at (800) 552-4821. For information see the website [www.wash.k12.mi.us/perform](http://www.wash.k12.mi.us/perform)

## Special Health Care

Local health departments provide information about **Children's Special Health Care Services (CSHCS)**. CSHCS helps to coordinate and pay for hospital and outpatient medical *specialty* care. Help may also be available for travel expenses related to a child's medical care. More than 2,000 diagnoses are eligible for coverage. For more information about CSHCS call (800) 359-3722.

Children with developmental disabilities who reside with their birth or adoptive parents and are in need of intensive community living supports and/or private duty nursing services may be eligible for the **Children's Waiver Program**. Contact your local Community Mental Health Services Program directly for more information. If you need the telephone number, call (517) 374-6848.

## Special Products

Advances in technology and new products help many children with special needs. **Michigan's Assistive Technology Resource (MATR)** has product information from more than 3,000 companies. Staff can help you find adaptive devices, special toys, clothing, equipment, and much more. Call (800) 274-7426, or see [www.cenmi.org/matr](http://www.cenmi.org/matr)

## Resources for Families of Infants and Toddlers with Special Health Needs



Michigan Department of Community Health  
Birth Defects Follow-up Program

## Early Intervention

One of the most important support systems for young children with special needs is called *Early On*<sup>®</sup> Michigan. It provides services for eligible children from birth to age three and their families regardless of income. The services may include:

- family training (skill building)
- counseling (family, group or individual)
- home visits
- special instruction (teaching)
- speech pathology
- audiology
- occupational therapy
- physical therapy
- psychological services
- service coordination
- diagnostic medical services
- early identification
- screening
- assessment services
- health services
- nursing services
- social work services
- vision services
- assistive technology devices and services
- nutritional counseling
- transportation

For more information, call (800) EARLY-ON (800-327-5966) voice and TDD; or visit [www.earlyonmichigan.org](http://www.earlyonmichigan.org)

## Special Education

Special education may help children who have physical, emotional, or mental conditions that prevent them from keeping up with others their age. Many services are offered free of charge by your public school system. **Project Find** helps to arrange a free evaluation through the local school district for any child who might need special education. For more information, call (800) 252-0052.

The **Center for Educational Networking** responds to the information needs of families, educators, and others who have a vested interest in the education of individuals with disabilities. Visit [www.cenmi.org](http://www.cenmi.org) to view the Michigan directory of services providers for infants, toddlers, and students with disabilities or call (800) 593-9146.

## Financial Support

*State and federal programs provide financial support to many families. Eligibility is usually based on the child's diagnosis and family income.*

**Supplemental Security Income (SSI)** is a federal program that provides monthly payments and enables state Medicaid coverage for children with severe mental, emotional and physical disabilities. The

family income must meet certain guidelines. To find out more, call the Social Security Administration at (800) 772-1213.

The **Family Support Subsidy Program** provides monthly payments to some families whose child is severely mentally or multiply impaired, or autistic impaired as determined by the public school system. To apply for the **Family Support Subsidy Program**, call your local Community Mental Health Services Program. If you need the number, call (517) 374-6848.

The **Children with Special Needs Fund** provides funds for equipment such as therapeutic tricycles or wheelchair ramps when there is no other source of payment. Families with a child enrolled or medically eligible to enroll in Children's Special Health Care Services (CSHCS) may apply at their local health department or by calling (800) 359-3722 or (517) 241-7420.

## Genetic Counseling

Genetics clinics offer evaluation and counseling. The clinic visit may provide information about a child's diagnosis, what to expect in the future, and whether the same condition could affect other people in the family. The Michigan Department of Community Health (MDCH) **Genetics Program** coordinates a network of genetics clinics in the state. Call toll-free (866) 852-1247 or visit [www.migeneticsconnection.org](http://www.migeneticsconnection.org) for more information.

## National Organizations

*Information about many different conditions, even rare ones, is available from national support organizations and information centers.*

To find out if there is a national group that deals with a child's diagnosis, call the **Genetic Alliance** at (202) 966-5557, or see [www.geneticalliance.org](http://www.geneticalliance.org)

The **MUMS: National Parent-to-Parent Network** connects families of children who have a rare diagnosis. Call (877) 336-5333, or see [www.netnet.net/mums](http://www.netnet.net/mums)

The **National Dissemination Center for Children with Disabilities (NICHCY)** is a clearinghouse that offers information, referral, and free publications to families of children with special health needs. Call (800) 695-0285, or see [www.nichcy.org](http://www.nichcy.org)

The **National Organization for Rare Disorders (NORD)** is dedicated to helping people with rare "orphan" diseases that affect only a small number of people. Call (800) 999-6673, or see [www.rarediseases.org](http://www.rarediseases.org) to access this information clearinghouse.

The **Fathers Network** celebrates and supports fathers and families raising children with special health care needs and developmental disabilities. For more information call (425) 747-4004 (x4286), or see [www.fathersnetwork.org](http://www.fathersnetwork.org)

## Birth Defects Prevention Resources

The National Center on Birth Defects and Developmental Disabilities at the **Centers for Disease Control and Prevention** offers a wide range of resources for families and professionals including the ABCs of having a healthy baby, basic facts about birth defects, birth defects research, folic acid promotion and fetal alcohol spectrum disorder. Follow the links at [www.cdc.gov/node.do/id/0900f3ec8000dffe](http://www.cdc.gov/node.do/id/0900f3ec8000dffe) for more information.

The mission of the **March of Dimes Birth Defects Foundation** is to improve the health of babies by preventing birth defects and infant mortality. Please visit [www.marchofdimes.com](http://www.marchofdimes.com) for a wealth of information on folic acid, prevention of prematurity, birth defects and genetics, and preparing for pregnancy.

The **National Birth Defects Prevention Network (NBDPN)** is a network of birth defects programs and individuals working at the local, state, and national level in birth defects surveillance, research and prevention. See [www.nbdpn.org](http://www.nbdpn.org) for annual 'Birth Defects Prevention Month' materials, surveillance reports and NTD/folic acid information.

Additional information and educational resources on folic acid are available from the **National Council on Folic Acid** at [www.folicacidinfo.org](http://www.folicacidinfo.org) and **Folicacid.net** at [www.folicacid.net](http://www.folicacid.net)

## Definitions and Technical Notes

**Birth defect:** an abnormal condition that occurs before or at the time of birth. Some birth defects are minor- such as the presence of an extra finger, while others are life-threatening, as in the case of a serious heart defect. Some birth defects are caused by genetic factors while others result from exposure to certain drugs, medications, or chemicals. The causes of many birth defects are still a mystery.

### Important factors to consider when viewing MBDR data

- Frequencies include all children reported with a birth defect who were born in Michigan and whose mother was a resident at the time of birth. This enables the calculation of birth defects incidence rates
- Columns do not add to diagnostic group totals nor column totals due to cases with multiple diagnosed conditions that cross diagnostic groupings
- Conditions are reportable if identified within the first two years of a child's life
- Diagnoses are coded using the 9th revision to the International Classification of Diseases- ICD 9 CM
- Diagnostic Code Groupings used for congenital anomaly codes are as used by the Centers for Disease Control and Prevention

### Data Quality Considerations

- The increased numbers of children diagnosed with hearing impairment in evidence since 1997 is related directly to a rapid increase in screening of Michigan newborns for hearing loss by birthing hospitals.
- Increases in frequency of endocrine and metabolic disorders since 1998 are due to coordination of case reporting with the Newborn Metabolic Screening Program.
- A change in ICD-9 CM coding added unique codes for hypospadias and epispadias in October of 1996. This is the cause of the discontinuity in the reported frequencies for these conditions as listed under the diagnostic grouping “H04 Hypospadias and Epispadias (75261, 75262)”.
- The completeness of data presented in MBDR tables is affected by three factors that relate to data accuracy and comparability. It is essential that these factors be considered in using the information, particularly when comparing frequencies over time or between geographic areas. These factors are:

#### Inconsistent or Incomplete Reporting

There is evidence that some facilities required to submit data are not reporting all the cases that should be reported. This problem can be expected to affect the completeness of the data within the specific regions of the state where these facilities are located. Very low birth defect frequencies and significant shifts in the number of reported cases can be expected for counties where such problems exist. Work beginning in 1999 to identify and resolve problems of under-reporting resulted in actual case counts increasing due to more complete information.

### **Over Reporting**

The ongoing review of reports received has identified that certain hospitals may submit cases of reportable diagnostic conditions which are later ruled out in a child, but the original report is not corrected accordingly. This can cause an over count of the number of cases. This problem can be expected to vary by facility which, in turn, can lead to geographic variations in case frequency counts for those areas where such facilities are located.

### **Resident Interstate Information Exchange is Lacking**

There is presently no exchange of data with neighboring states on children born with birth defects. Such exchange does occur with vital records and cancer information. Thus, birth defects cases are unreported whenever a Michigan child is diagnosed with, or treated for, a birth defect in a facility not in Michigan. This problem will cause an undercount of the actual number of cases and can be expected to significantly affect the completeness of reports for counties whose residents commonly travel outside Michigan for their health care. Due to the lack of interstate resident information exchange, rates are calculated only for resident children who are also born in Michigan.



## Acknowledgements

*The MDCH Birth Defects Program gratefully acknowledges the many individuals and organizations that contribute to Michigan's birth defects surveillance system and extends special thanks to our friends at the Centers for Disease Control and Prevention for their leadership, support and technical assistance:*

### **MBDR Staff,**

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Helen Sanders  
Phyllis Strong

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Hospitals  
Cytogenetic laboratories

Pediatric and reproductive genetic centers

### **MDCH Birth Defects Steering Committee and partner programs,**

For their advice and counsel on registry goals, directions and assistance and coordination with registry efforts

Children's Special Health Care Services  
Early Hearing Detection and Intervention  
Early On  
FAS Prevention Project

Newborn Screening  
Pregnancy Risk Assessment Monitoring  
System  
WIC Nutrition Program

### **National Center on Birth Defects and Developmental Disabilities,**

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Cara Mai  
Leslie O'Leary  
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## *Appendices*

- A. MBDR Advisory Panel**
- B. Birth Defects Program Fact Sheet**
- C. Reportable Conditions by Diagnostic Category**
- D. Hospital Birth Defects Reporting Form**
- E. Cytogenetics Laboratory Birth Defects Reporting Form**
- F. MBDR Data, 1992-2002**

**Table 1.** Birth Defects by Detailed Diagnostic Group and Birth Year, 1992-2002

**Table 2.** Birth Defects Prevalence Rates by Diagnostic Group and by Birth Year, 1992-2002

**Table 3.** Infant Deaths to Michigan Children with Reported Birth Defects and Mortality Rates by Diagnostic Group and Birth Year, 1992-2002

**Table 4.** Infant Death Rates to Michigan Children with Reported Birth Defects and Mortality Rates by Diagnostic Group and by Birth Year, 1992-2002

### **G. Mapping of Birth Defects by County**

**Figure 1.** Map of neural tube defects by county in Michigan between 1992-2002

**Table 1.** Prevalence of neural tube defects by county in Michigan between 1992-2002

**Figure 2.** Map of orofacial clefts by county in Michigan between 1992-2002

**Table 2.** Prevalence of orofacial clefts by county in Michigan between 1992-2002

**Figure 3.** Map of Down syndrome by county in Michigan between 1992-2002

**Table 3.** Prevalence of Down syndrome by county in Michigan between 1992-2002

**Figure 4.** Map of congenital heart defects by county in Michigan between 1992-2002

**Table 4.** Prevalence of congenital heart defects by county in Michigan between 1992-2002

## Appendix A

### Working Group for the Michigan Birth Defects Registry (MBDR) Pilot Project

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# Birth Defects Prevention, Monitoring & Follow-up

*Michigan's Birth Defects Program includes three important components:*

## Prevention

Includes identifying ways to prevent certain birth defects and educating communities and health professionals about prevention strategies. Up to 70% of neural tube defects (NTD) such as spina bifida can be prevented by adequate folic acid intake during the first month of pregnancy. Other birth defects that can be prevented are caused by certain maternal illnesses, infections, or exposures such as alcohol. MDCH collaborates with many partners to address prevention, including the March of Dimes, reproductive genetic centers,

and the National Birth Defects Prevention Network. Key activities include:

- A folic acid educational campaign
- Promoting prevention strategies during national Birth Defects Prevention Month
- Disseminating informational materials including a free pamphlet, *Preventing Birth Defects—Important Information for Michigan Families*
- Conducting outreach to special populations and high risk groups

- For information on folic acid or birth defects prevention, contact Nelda Mercer, MS, RD, at (517) 335-8887 or [mercern5@michigan.gov](mailto:mercern5@michigan.gov)

## Monitoring

Is provided by the Michigan Birth Defects Registry (MBDR), established in 1992 by state law to track the occurrence of over 800 types of birth defects across the state. The confidential registry is a passive system that relies on reports submitted by hospitals and cytogenetic laboratories within 30 days of a child's diagnosis. Reportable conditions include structural malformations as well as genetic disorders and

other selected diseases occurring in children from birth through 24 months of age. About 10,000 Michigan children are born each year with birth defects or other reportable conditions. The MBDR currently contains 286,000 reports on approximately 143,000 children. An epidemiologist analyzes registry data and conducts special studies to better understand the impact of birth defects on public health.

- To find statistical birth defect data summaries, visit [www.mdch.state.mi.us/pha/osr/](http://www.mdch.state.mi.us/pha/osr/). To request data by specific geographic region or other demographic parameters, contact Glenn Copeland at (517) 335-8677 or [copelandg@michigan.gov](mailto:copelandg@michigan.gov)

## Follow-up

Includes identifying the special needs of children with birth defects, and making sure families are connected with available resources and support systems. Providing information to families in a timely manner while preserving the privacy of birth defects data is a top priority. A study has been conducted in selected Michigan hospitals to help identify the most useful and sensitive approach to providing follow-up based on gaps

in existing referral systems. The program maintains a genetic support group directory and distributes a pamphlet, *Resources for Families of Infants and Toddlers with Special Health Needs* at no cost to hospitals, health professionals and families. Follow-up on infants with neural tube defects began in 2004 and a parent handbook is being developed.

- To find information on services for children with birth defects, contact Jane Simmermon, RN, MPH toll-free at 1-866-852-1247 or (517) 335-8887; or e-mail [BDRFollowup@michigan.gov](mailto:BDRFollowup@michigan.gov)

## Appendix C

	<b>Conditions Reportable to the Michigan Birth Defects Registry</b>
A	Congenital Anomalies of the Central Nervous System (740-742)
B	Congenital Anomalies of the Eye (743)
C	Congenital Anomalies of the Ear, Face and Neck (744)
D	Congenital Anomalies of the Heart and Circulatory System (745-746)
E	Congenital Anomalies of the Respiratory System (747-748)
F	Cleft Palate and Cleft Lip (749)
G	Congenital Anomalies of the Upper Alimentary Canal/Digestive System (750-751)
H	Congenital Anomalies of the Genital and Urinary Systems (752-753)
I	Congenital Anomalies of the Musculoskeletal System (754-756)
J	Congenital Anomalies of the Integument (757)
K	Chromosomal Anomalies (758)
L	Other and Unspecified Congenital Anomalies (759)
M	Infectious Conditions Occurring in the Perinatal Period (09.00-096.09, 771.0-771.2)
N	Familial/Congenital Neoplasms (237.70-237.72)
O	Endocrine/Metabolic Disorders (243, 252.00-252.08, 252.1, 253.2, 253.8, 255.2, 255.8, 257.8, 259.4, 270.0-273.9, 275.3, 277.0-277.9, 279.11, 279.2)
P	Diseases of the Blood and Blood Forming Organs (282.0-282.9, 284.0, 286.0-286.9, 287.3)
Q	Other Diseases of the Central and Peripheral Nervous System (330.1, 331.7, 331.89, 331.9, 334.1, 334.2, 335.0, 337.9, 343.0-343.9, 345.6, 348.0, 352.6, 356.0-356.9, 358.0-359.9)
R	Other diseases of the Eye (362.60-362.66, 363.20, 369.00-369.9, 377.16, 378.0-378.9, 379.50-379.59)
S	Hearing Deficiency (389.9)
T	Other Diseases of the Heart and Circulatory System (425.0-425.4, 426.0, 426.10-427.42, 427.81-427.9, 434.0-434.9, 453.0)
U	Other Diseases of the Gastrointestinal System (520.0-520.9, 524.00-524.19, 537.1, 550.00-550.93, 553.00-553.9, 560.2, 560.9, 565.1, 569.2, 569.81)
V	Other Diseases of the Genital and Urinary Systems (593.3, 593.5, 593.82, 596.1, 596.2, 596.9, 599.1, 599.6, 619.0-619.9)
W	Other Fetal/Placental Anomalies (653.7, 658.8)
X	Other Musculoskeletal system Diseases (733.3)
Y	Maternal Exposures Affecting the Fetus (760)

## Appendix D

# MICHIGAN BIRTH DEFECTS REGISTRY REPORT

Vital Records and Health Data Development Section  
Michigan Department of Community Health

□ Correction

1. Name of Child		(Last)	(First)	(Middle Initial)
2. If the child has been identified by another name (AKA – also known as)				
3. Child's Current Street Address			Apartment No.	P.O. Box No.
City		State	Zip Code	Telephone No.
4. Child's Social Security Number (if known)	5. Medical record Number		6. Sex  <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Undesignated	7. Plurality  <input type="checkbox"/> Single <input type="checkbox"/> First <input type="checkbox"/> Second <input type="checkbox"/> Third or More
8. Child's Medicaid # (if known)	9. Date of Birth (Month) (Day) (Year)			
10. Hospital / Place of Birth				
City		State	11. Mother's Social Security Number	
12. Mother's Name		(Last)	(First)	(Middle Initial)
13. Name of Facility Submitting Form		City	State	
14. Patient Status  <input type="checkbox"/> Inpatient <input type="checkbox"/> Outpatient	15. Admission Status  <input type="checkbox"/> Any Admission <input type="checkbox"/> Transferred	16. Admission Date (Month) (Day) (Year)	17. Discharge Status  <input type="checkbox"/> Alive <input type="checkbox"/> Transferred <input type="checkbox"/> Dead	18. Discharge Date (Month) (Day) (Year)
19. Procedure Codes – ICD-9-CM Codes				
(attach additional forms as needed)				
20. Diagnoses (attach additional forms if more than 5 diagnoses)			ICD-9-CM Code	
1. _____			_____	
2. _____			_____	
3. _____			_____	
4. _____			_____	
5. _____			_____	
Syndrome _____			_____	
21. Cytogenetics			ICD-9-CM Code	
<input type="checkbox"/> Not Stated <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Pending <input type="checkbox"/> No Growth <input type="checkbox"/> Not Done				
If Abnormal, Describe			ICD-9-CM Code	

22. Name of Laboratory		City
23. Name of Person Completing Form		
(Last)	_____	(First) _____
Telephone Number	_____	

DCH-0944W (2/02)  
Authority: PA 236 of 1988  
Confidentiality assured by P.A. 368 of 1978  
being MCL 333.2631-2633

Please return to: Michigan Department of Community Health  
Population and Provider Data Unit  
3423 N. Martin Luther King Jr., Blvd.  
P.O. Box 30691  
Lansing, MI 48909

## INSTRUCTIONS FOR COMPLETING THE BIRTH DEFECTS REGISTRY REPORT FORM

Accuracy and thoroughness in case identification and data abstracting determine the quality of the data and the usefulness of a registry. The quality of the information reported is dependent on the ability of personnel to abstract relevant data from the hospital chart.

It is important to fill out the form completely and as accurately as possible. The majority of the information requested on the Michigan Birth Defects Registry report form is self-explanatory. However, each item is reviewed to offer further clarification and provide a rationale for collection. To minimize the time required to complete the form, the number of data items is restricted to include only information deemed necessary for demographic and diagnostic analysis.

### ITEM REVIEW

#### Initial and Follow-up Report

- Please review the patient's medical record to determine if a Birth Defects Registry report has been filed. **If one has been filed and the diagnosis has changed, please file a follow-up report. If you are not sure, please file a report.**
  - Check the box in the top left hand corner to indicate if this is an initial report or a follow-up report.
  - Enter month, day, and year the form was completed.
1. **Child's Name**  
Enter the child's last name, first name and middle initial. If the child was not named, indicate name used on medical chart.
  2. **AKA – Also Known As**  
Enter any other name by which the child is also known. Give last name, first name and middle initial. Write "unknown" if there is no indication that the child has been known by any other name.
  3. **Child's Address and Telephone Number**  
Enter the number and street, area code, telephone number, city, state and zip code where the child presently resides (or will reside when discharged). When there is no telephone at the residence, write "unknown."
  4. **Child's Social Security Number**  
If a social security number for the child is not available, write "unknown."
  5. **Medical Record Number**  
Enter the child's medical record number as assigned by your facility.
  6. **Sex**  
Enter an "X" in the appropriate box indicating male, female or undesignated. One of the boxes must be checked.
  7. **Plurality**  
Indicate if the child was a single birth, first, second, or third or more.
  8. **Child's Medicaid Number**  
Enter the child's Medicaid number. If a child does not have a Medicaid number listed in available records, write "unknown."
  9. **Date of Birth**  
Enter the child's numerical date of birth (month, day, year). If the date of birth is not in the medical record, attach a note stating reason for absence.

**10. Hospital, City and State of Birth**

Enter the city, county and state where the child was born. If it is impossible to determine this information, write “unknown.”

**11. Mother’s Social Security Number**

Enter the mother’s social security number. If not determined, write “unknown.”

**12. Mother’s Name**

Enter the current last name, first name and middle initial of the child’s natural mother. If it is impossible to determine this information, write “unknown.”

**13. Hospital/Place of Diagnosis and City**

Enter the full name of the facility, city and state from which this report is being generated.

**14. Patient Status**

Enter an “X” in the appropriate box indicating inpatient or outpatient.

**15. Admission Status**

Enter an “X” in the appropriate box indicating if patient was transferred from another facility or if admitted in any other circumstance.

**16. Admission Date**

Enter the date the patient was admitted to the facility (or born in the facility).

**17. Discharge Status**

Enter an “X” indicating if patient was discharged alive, deceased or to another facility.

**18. Discharge Date**

Enter month, day and year patient was discharged.

**19. Procedure Codes**

Report all procedure codes (up to fifteen) using ICD-9-CM procedure listing.

**20. Diagnoses**

- List **ALL** reportable diagnoses. **Do not report “V codes”**. List each diagnosis separately on a corresponding numbered line. Almost all items in the congenital Anomalies section of the ICD-9-CM are reportable to the Michigan Birth Defects Registry. In addition, parts of other sections are reportable. These include inborn errors of metabolism, some endocrine disorders, hereditary blood, eye, nervous system and muscle disorders. Certain conditions in the perinatal period such as congenital rubella are required. **Please refer to Section II for a detailed list of reportable conditions.**
- Report only permanent conditions. Do not report transient conditions like transient hypoglycemia and hyperbilirubinemia of the newborn. There are diagnoses that are not collected by the Michigan Birth Defects Registry such as retinopathy of prematurity, ankyloglossia, umbilical hernia completely covered by skin and gastroesophageal reflux (chalasia). **Please refer to Section II for a listing of conditions that are not reportable if occurring alone without any other reportable defect.**
- Enter the **exact words** used by the physician to describe the condition. **Quote the portions of the medical record where the diagnosis is explained in the most detailed, complete terms.** Try to be as specific as possible in your written description, with respect to location, bilateral, unilateral involvement and size of certain conditions. For example, “limb reduction” is not sufficient for coding. Instead, it is desirable to write “absence of upper arm and forearm with hand present, bilateral involvement.”

- **Do not submit congenital anomaly data in the form of an ICD-9CM code** as many of these ICD codes include very common minor defects and rarer major defects. The surveillance system wishes to have individual entities and not grouped entities.
- **Do not use abbreviations in your reporting.** For example, “CHD” or “CDH” will cause confusion. Instead, report “congenital heart disease” or “congenital dislocation of the hip.” Avoid using words like “possible, query, borderline, likely, transient, suspect, ?,” etc. Report confirmed diagnosis whenever possible.
- **Once a reportable condition is found** within a patient’s medical record, carefully check for additional reportable conditions that may be listed elsewhere in the medical record.
- **Congenital heart disease** is a descriptive term that encompasses many different types of congenital heart defects. Please provide as much information as possible on specific heart defects. For example, patent ductus arteriosus, pulmonary valvular stenosis or Tetralogy of Fallot instead of congenital heart disease.
- The reporting of hip anomalies appears to be a difficult task and currently there is little agreement among orthopedic surgeons over which hip problems are congenital anomalies. **Please report all hip anomalies except 754.32 and 754.33** “Subluxation of the hip – unilateral and bilateral.”
- **Jaundice**, on its own, is a frequent condition that is not reportable to the Registry. However, if there is some underlying cause for the jaundice, such as glycogen storage disease or congenital biliary atresia, etc. **please report these underlying conditions.**
- Another frequent reporting problem is that of tyrosine where it is mentioned as being increased or elevated or transient elevation. These events are extremely common and quite normal especially in premature infants. With a little vitamin C, the tyrosine metabolism is restored to normality. There is, however, a very rare inborn error of metabolism involving tyrosine that is hereditary tyrosinemia or tyrosinosis. These inborn errors of metabolism should be reported to the Registry.
- **If there is a syndrome diagnosis**, list both the syndrome name and all the individual anomalies that comprise the syndrome. It is still necessary to describe each component defect individually as it appears in the medical record for coding.

## ICD-9-CM Code

List the ICD-9-CM code assigned by your facility

### 21. Cytogenetics

- Put an “X” in the box which best describes the chromosome testing status of the case.
- Check “not stated” if you are uncertain as to whether a cytogenetics study was performed or requested.
- The box listed as “normal” is reserved for cases that have had a cytogenetics study done, and the results are described as “normal.”
- If the labeled “abnormal” is checked, it should be followed by a complete description of the abnormality on the line below. Do not use abbreviations in this description.
- If there is an indication that a cytogenetics study was requested but there are no results, put an “X” in the box labeled “pending.”
- The box listed as “no growth” is reserved for cases that have had a cytogenetics study done, and the results are described as “no growth.”
- If it is known that cytogenetics study was not requested or performed, put an “X” in the box labeled “not done.”

**22. Name of Laboratory and City**

- Give the name of the laboratory where the cytogenetics study was sent or performed. Include the city where the laboratory is located.
- If you checked the boxes labeled “not stated”, “normal”, “Pending” or “no growth” but are uncertain which laboratory is performing the test, put a “U” in the first box. If you checked the box labeled “not done” write “none” next to the first four boxes.

**23. Person Completing Form**

Enter the last name and first name in the spaces provided. Enter the area code and telephone number of the medical records department where you can be reached.

## Appendix E

### MICHIGAN BIRTH DEFECTS REGISTRY CYTOGENETICS REPORT

2. <u>If the Child has been identified by another name (AKA - also known as)</u>			
3. <u>Child's Current Street Address</u>  _____  <u>City</u>  _____		<u>Apartment NO.</u>  _____  <u>State</u>  _____	<u>PO Box NO</u>  _____  <u>Zip Code</u>  _____
4. Child's Social Security Number (if known)  _____	6. Medical Record NO.  _____	8. Sex: <input style="width: 100%;" type="text"/> Male <input style="width: 100%;" type="text"/> Female <input style="width: 100%;" type="text"/> Undesignated <input style="width: 100%;" type="text"/> 9 DECEASED <input style="width: 100%;" type="text"/> YES <input style="width: 100%;" type="text"/> NO	10. Plurality <input style="width: 100%;" type="text"/> Single <input style="width: 100%;" type="text"/> First <input style="width: 100%;" type="text"/> Second <input style="width: 100%;" type="text"/> Third or More
5. Child's Medicaid Number (If known)  _____			
7. Date of Birth (Month)      (Day)      (Year)  _____			
11. HOSPITAL - PLACE OF BIRTH			
12.                      CITY                                      COUNTY                                      STATE			
13.    MOTHER'S LAST NAME                                      FIRST NAME                                      M.I.                                      SOCIAL SECURITY NO.  _____			
14.    HOSPITAL - PLACE OF DIAGNOSIS                                      CITY                                      STATE			
15. <u>CYTOGENETICS</u> - DESCRIBE FINDINGS:                                      ICD - 9 - CM CODE  _____  _____  _____			
16.    NAME OF LABORATORY		17.    CITY	
18. <u>LAST NAME</u> OF PERSON COMPLETING THIS FORM  (LAST)		<u>FIRST NAME</u> OF PERSON COMPLETING THIS FORM  (FIRST)	
TELEPHONE NUMBER:  _____		DATE COMPLETED:  (Month) _____ (Day) _____ (Year) _____	

DCH-0944W (2/02)  
PA 236 of 1988  
Confidentiality assured by P.A. 368 of 1978  
being MCL 333.2631-2633

Please return to: Michigan Department of Community Authority:  
Population Health & Provider Data Unit  
3423 N. Martin Luther King Jr., Blvd.  
P.O. Box 30691; Lansing, MI 48909,



## Appendix F

**Table 1: Birth Defects by Detailed Diagnostic Group and Birth Year**  
**Michigan Resident Children Born in Michigan, 1992 through 2002**  
**Cases Diagnosed within One Year from Birth**

Congenital Anomalies (740 - 759)													
Diagnostic Grouping (ICD-9 CM Diagnostic Code)	All Years	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	
<b>Congenital Anomalies of the Central Nervous System (740-742)</b>	<b>4,049</b>	<b>444</b>	<b>418</b>	<b>385</b>	<b>372</b>	<b>318</b>	<b>373</b>	<b>361</b>	<b>435</b>	<b>466</b>	<b>477</b>	<b>467</b>	
<b>Anencephalus (7400,7401)</b>	<b>120</b>	<b>12</b>	<b>12</b>	<b>15</b>	<b>13</b>	<b>5</b>	<b>11</b>	<b>12</b>	<b>12</b>	<b>21</b>	<b>7</b>	<b>14</b>	
<b>Spina Bifida w/o Anencephaly ( 7410, 7419 w/o 7400, 7401)</b>	<b>556</b>	<b>54</b>	<b>65</b>	<b>51</b>	<b>64</b>	<b>51</b>	<b>52</b>	<b>50</b>	<b>51</b>	<b>49</b>	<b>69</b>	<b>41</b>	
<b>Hydrocephalus w/o Spina Bifida (7423 w/o 7410, 7419)</b>	<b>1,204</b>	<b>146</b>	<b>128</b>	<b>121</b>	<b>101</b>	<b>92</b>	<b>111</b>	<b>100</b>	<b>133</b>	<b>134</b>	<b>138</b>	<b>122</b>	
<b>Encephalocele (7420)</b>	<b>137</b>	<b>21</b>	<b>20</b>	<b>18</b>	<b>12</b>	<b>12</b>	<b>9</b>	<b>7</b>	<b>10</b>	<b>16</b>	<b>12</b>	<b>12</b>	
<b>Microcephalus (7421)</b>	<b>904</b>	<b>92</b>	<b>73</b>	<b>90</b>	<b>91</b>	<b>75</b>	<b>76</b>	<b>75</b>	<b>104</b>	<b>118</b>	<b>110</b>	<b>126</b>	
<b>All Other CNS Anomalies</b>	<b>1,768</b>	<b>197</b>	<b>171</b>	<b>162</b>	<b>159</b>	<b>124</b>	<b>180</b>	<b>165</b>	<b>196</b>	<b>197</b>	<b>217</b>	<b>224</b>	
<b>Congenital Anomalies of the Eye (743)</b>	<b>2,842</b>	<b>279</b>	<b>272</b>	<b>233</b>	<b>242</b>	<b>219</b>	<b>241</b>	<b>309</b>	<b>331</b>	<b>367</b>	<b>349</b>	<b>347</b>	
<b>Anaphthalmia/Microphthalmia (74300-74306, 74310-74312)</b>	<b>204</b>	<b>20</b>	<b>15</b>	<b>18</b>	<b>22</b>	<b>17</b>	<b>19</b>	<b>27</b>	<b>20</b>	<b>19</b>	<b>27</b>	<b>30</b>	
<b>Congenital Cataract (74330 - 74334)</b>	<b>254</b>	<b>19</b>	<b>26</b>	<b>21</b>	<b>25</b>	<b>29</b>	<b>19</b>	<b>24</b>	<b>28</b>	<b>35</b>	<b>28</b>	<b>33</b>	
<b>Aniridia (74345)</b>	<b>20</b>	<b>1</b>	<b>1</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>4</b>	<b>1</b>	<b>3</b>	<b>2</b>	<b>2</b>	
<b>All Other Congenital Anomalies of the Eye</b>	<b>2,523</b>	<b>249</b>	<b>247</b>	<b>198</b>	<b>206</b>	<b>191</b>	<b>215</b>	<b>268</b>	<b>298</b>	<b>334</b>	<b>317</b>	<b>307</b>	
<b>Congenital Anomalies of the Ear, Face and Neck (744)</b>	<b>2,132</b>	<b>274</b>	<b>250</b>	<b>257</b>	<b>215</b>	<b>165</b>	<b>200</b>	<b>176</b>	<b>171</b>	<b>208</b>	<b>216</b>	<b>207</b>	
<b>Anotia/Microtia (74401,74423)</b>	<b>109</b>	<b>11</b>	<b>11</b>	<b>8</b>	<b>9</b>	<b>5</b>	<b>9</b>	<b>9</b>	<b>19</b>	<b>13</b>	<b>15</b>	<b>16</b>	
<b>All Other Congenital Anomalies of the Ear, Face and Neck</b>	<b>2,091</b>	<b>268</b>	<b>246</b>	<b>257</b>	<b>210</b>	<b>162</b>	<b>197</b>	<b>171</b>	<b>163</b>	<b>204</b>	<b>213</b>	<b>200</b>	
<b>Congenital Anomalies of the Heart and Circulatory System (745-746)</b>	<b>20,037</b>	<b>1854</b>	<b>2033</b>	<b>2215</b>	<b>1860</b>	<b>2038</b>	<b>2011</b>	<b>1939</b>	<b>1977</b>	<b>2007</b>	<b>2103</b>	<b>2157</b>	
<b>Common Truncus (7450)</b>	<b>161</b>	<b>17</b>	<b>15</b>	<b>19</b>	<b>9</b>	<b>12</b>	<b>24</b>	<b>18</b>	<b>15</b>	<b>16</b>	<b>16</b>	<b>13</b>	
<b>Transposition of Great Arteries (74510, 74511, 74512, 74519)</b>	<b>620</b>	<b>68</b>	<b>62</b>	<b>67</b>	<b>50</b>	<b>54</b>	<b>65</b>	<b>64</b>	<b>53</b>	<b>79</b>	<b>58</b>	<b>66</b>	
<b>Teralogy of Fallot (7452)</b>	<b>714</b>	<b>74</b>	<b>72</b>	<b>81</b>	<b>64</b>	<b>71</b>	<b>73</b>	<b>75</b>	<b>69</b>	<b>71</b>	<b>64</b>	<b>61</b>	
<b>Ventricular Septal Defect (7454)</b>	<b>5,213</b>	<b>569</b>	<b>572</b>	<b>571</b>	<b>479</b>	<b>502</b>	<b>507</b>	<b>555</b>	<b>498</b>	<b>491</b>	<b>469</b>	<b>482</b>	
<b>Atrial Septal Defect (7455)</b>	<b>6,606</b>	<b>431</b>	<b>500</b>	<b>651</b>	<b>641</b>	<b>709</b>	<b>698</b>	<b>702</b>	<b>727</b>	<b>765</b>	<b>782</b>	<b>851</b>	
<b>Endocardial Cushion Defect (74560, 74561, 74569)</b>	<b>533</b>	<b>52</b>	<b>45</b>	<b>59</b>	<b>48</b>	<b>59</b>	<b>65</b>	<b>51</b>	<b>50</b>	<b>53</b>	<b>51</b>	<b>54</b>	
<b>Pulmonary Valve Atresia and Stenosis (74601, 74602)</b>	<b>1,404</b>	<b>133</b>	<b>134</b>	<b>161</b>	<b>109</b>	<b>138</b>	<b>146</b>	<b>137</b>	<b>152</b>	<b>141</b>	<b>153</b>	<b>113</b>	
<b>Tricuspid Valve Atresia and Stenosis (7461)</b>	<b>181</b>	<b>17</b>	<b>15</b>	<b>17</b>	<b>13</b>	<b>15</b>	<b>20</b>	<b>13</b>	<b>16</b>	<b>27</b>	<b>28</b>	<b>24</b>	
<b>Ebstein's Anomaly (7462)</b>	<b>176</b>	<b>13</b>	<b>12</b>	<b>6</b>	<b>5</b>	<b>8</b>	<b>13</b>	<b>12</b>	<b>21</b>	<b>39</b>	<b>47</b>	<b>35</b>	
<b>Aortic Valve Stenosis (7463)</b>	<b>283</b>	<b>34</b>	<b>27</b>	<b>26</b>	<b>22</b>	<b>19</b>	<b>24</b>	<b>29</b>	<b>41</b>	<b>39</b>	<b>22</b>	<b>28</b>	
<b>Hypoplastic Left Heart Syndrome (7467)</b>	<b>497</b>	<b>54</b>	<b>47</b>	<b>42</b>	<b>47</b>	<b>42</b>	<b>53</b>	<b>45</b>	<b>50</b>	<b>52</b>	<b>65</b>	<b>52</b>	
<b>Patent Ductus Arteriosus (7470)</b>	<b>6,159</b>	<b>620</b>	<b>682</b>	<b>783</b>	<b>631</b>	<b>687</b>	<b>593</b>	<b>522</b>	<b>557</b>	<b>516</b>	<b>568</b>	<b>585</b>	

# Appendix F

**Table 1: Birth Defects by Detailed Diagnostic Group and Birth Year**  
**Michigan Resident Children Born in Michigan, 1992 through 2002**  
**Cases Diagnosed within One Year from Birth (continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	All Years	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
<b>Congenital Anomalies of the Heart and Circulatory System - continued (745-746)</b>												
Coarctation of Aorta (74710)	712	67	63	56	57	74	65	81	87	90	72	80
Pulmonary Artery Anomalies (7473)	2,149	149	203	215	176	191	225	216	239	258	277	269
All Other Congenital Anomalies of the Heart and Circulatory System	8,642	839	856	912	730	905	958	843	860	864	875	948
<b>Congenital Anomalies of the Respiratory System (747 - 748)</b>	4,039	442	401	423	303	295	317	351	410	521	576	557
Lung Agenesis/Hypoplasia (7485)	751	78	72	67	62	67	67	90	93	85	70	69
Choanal Atresia (7480)	202	24	22	14	15	20	18	22	20	20	27	27
All Other Congenital Anomalies of the Respiratory System	3,346	370	336	361	246	229	254	272	324	443	511	500
<b>Cleft Palate and Cleft Lip (749)</b>	2,001	231	189	182	186	183	213	198	215	201	203	180
Cleft Palate (74900 - 74904 w/o Cleft Lip 7491, 7492)	714	79	67	71	69	68	69	74	73	72	72	58
Cleft Lip w and w/o Cleft Palate (7491, 7492)	1,287	152	122	111	117	115	144	124	142	129	131	122
<b>Congenital Anomalies of the Upper Alimentary Canal/ Digestive System (750-751)</b>	6,472	710	751	640	583	634	611	632	623	621	667	602
Esophageal Atresia/Tracheoesophageal Fistula (7503)	489	40	114	46	51	39	44	37	45	32	41	40
Rectal and Large Intestinal Atresia/Stenosis (7512)	619	74	53	54	65	65	52	66	62	71	57	59
Pyloric Stenosis (7505)	2,498	299	247	245	200	236	250	264	256	224	277	237
Hirschsprung's Disease (congenital megacolon) (7513)	407	43	43	35	29	45	36	47	47	39	43	39
Biliary Atresia (75161)	180	17	25	14	21	22	13	17	17	19	15	9
Other Cong. Anomalies of Upper Alimentary Canal/ Digestive System	2,713	280	317	284	260	282	251	252	238	282	267	258
<b>Congenital Anomalies of the Genital and Urinary Systems (752 - 753)</b>	13,649	1445	1444	1515	1363	1227	1149	1109	1327	1589	1481	1472
Renal Agenesis/Hypoplasia (7530)	708	66	62	71	63	75	69	70	75	93	64	77
Bladder Exstrophy (7535)	55	6	8	5	7	7	3	4	3	3	9	6
Obstructive Genitourinary Defects (75320-75329, 7536)	2,243	219	186	203	218	223	224	198	232	262	278	287
Hypospadias and Epispadias (75261, 75262)	2,168	1	3	7	67	153	365	354	401	431	386	376
All Other Congenital Anomalies of the Genital and Urinary Systems	13,649	1445	1444	1515	1363	1227	1149	1109	1327	1589	1481	1472

## Appendix F

**Table 1: Birth Defects by Detailed Diagnostic Group and Birth Year**  
**Michigan Resident Children Born in Michigan, 1992 through 2002**  
**Cases Diagnosed within One Year from Birth (continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	All Years	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
<b>Congenital Anomalies of the Musculoskeletal System (754 - 756)</b>	<b>18,008</b>	<b>2110</b>	<b>1976</b>	<b>1860</b>	<b>1547</b>	<b>1533</b>	<b>1568</b>	<b>1563</b>	<b>1735</b>	<b>2000</b>	<b>2116</b>	<b>2101</b>
Upper Limb Reduction Deformities (75520 - 75529)	351	62	39	33	31	27	33	26	33	37	30	32
Lower Limb Reduction Deformities (75530 - 75539)	199	23	14	23	21	20	16	15	20	20	27	22
Gastroschisis/Omphalocele (7567)	538	57	73	88	69	73	50	38	28	30	32	19
Congenital Hip Dislocation (75430, 75431, 75435)	1,901	251	213	211	183	174	165	162	161	190	191	186
Diaphragmatic Hernia (7566)	410	51	41	39	39	41	36	37	45	38	43	30
All Other Congenital Anomalies of the Musculoskeletal System	15,461	1755	1684	1565	1287	1287	1348	1338	1526	1773	1898	1934
<b>Congenital Anomalies of the Integument (757)</b>	<b>3,363</b>	<b>418</b>	<b>398</b>	<b>429</b>	<b>334</b>	<b>335</b>	<b>314</b>	<b>254</b>	<b>299</b>	<b>291</b>	<b>291</b>	<b>287</b>
<b>Chromosomal Anomalies (758)</b>	<b>2,694</b>	<b>313</b>	<b>286</b>	<b>273</b>	<b>228</b>	<b>263</b>	<b>237</b>	<b>231</b>	<b>288</b>	<b>288</b>	<b>287</b>	<b>262</b>
Trisomy 13 (7581)	144	22	22	13	11	12	16	10	13	15	10	9
Down Syndrome (7580)	1,499	173	152	158	129	138	138	137	150	150	174	161
Trisomy 18 (7582)	179	22	20	15	18	16	12	16	26	14	20	19
All Other Chromosomal Anomalies	985	106	101	95	77	103	80	80	115	128	100	93
<b>Other and Unspecified Congenital Anomalies (759)</b>	<b>3,366</b>	<b>364</b>	<b>276</b>	<b>236</b>	<b>161</b>	<b>171</b>	<b>252</b>	<b>282</b>	<b>361</b>	<b>564</b>	<b>699</b>	<b>597</b>
<b>Other Reportable Conditions</b>												
<b>Infectious Conditions Occurring in the Perinatal Period (0900 - 0909, 7710 - 7712)</b>	<b>1,538</b>	<b>209</b>	<b>224</b>	<b>174</b>	<b>128</b>	<b>91</b>	<b>130</b>	<b>128</b>	<b>131</b>	<b>155</b>	<b>168</b>	<b>159</b>
Syphilis (0900-0909)	614	159	148	78	48	30	45	47	15	18	26	12
Other Infections (7710 - 7712)	930	54	78	96	80	61	85	81	116	137	142	147
<b>Familial/Congenital Neoplasms (23770 - 23772)</b>	<b>110</b>	<b>7</b>	<b>12</b>	<b>11</b>	<b>9</b>	<b>8</b>	<b>10</b>	<b>12</b>	<b>13</b>	<b>15</b>	<b>13</b>	<b>12</b>
<b>Endocrine/Metabolic Disorders (243, 2521, 2532, 2538, 2552, 2558, 2578, 2594, 2700 - 2739, 2753, 2770 - 2779, 27911, 2792)</b>	<b>3,312</b>	<b>261</b>	<b>303</b>	<b>291</b>	<b>263</b>	<b>307</b>	<b>275</b>	<b>321</b>	<b>420</b>	<b>458</b>	<b>413</b>	<b>397</b>
<b>Diseases of the Blood and Blood Forming Organs (2820 - 2829, 2840, 2860 - 2869, 2873)</b>	<b>1,989</b>	<b>188</b>	<b>212</b>	<b>212</b>	<b>213</b>	<b>181</b>	<b>175</b>	<b>177</b>	<b>202</b>	<b>238</b>	<b>191</b>	<b>206</b>
<b>Other Diseases of the Central and Peripheral Nervous System (3301, 3317, 33189, 3319, 3341, 3342, 3350, 3379, 3430 - 3439, 3456, 3480, 3526, 3560 - 3569, 3580 - 3599)</b>	<b>1,882</b>	<b>176</b>	<b>173</b>	<b>177</b>	<b>162</b>	<b>165</b>	<b>157</b>	<b>178</b>	<b>232</b>	<b>240</b>	<b>222</b>	<b>202</b>

## Appendix F

**Table 1: Birth Defects by Detailed Diagnostic Group and Birth Year  
Michigan Resident Children Born in Michigan, 1992 through 2002  
Cases Diagnosed within One Year from Birth (continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	All Years	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
Other Diseases of the Eye (36260 - 36266, 36320, 36900 - 3699, 37716, 3780 - 3789, 37950 - 37959)	5,283	318	473	514	481	551	531	504	667	634	610	576
Hearing Deficiency (3899)	1,051	29	26	28	28	34	57	103	161	271	314	309
Other Diseases of the Heart and Circulatory System (4250 - 4254, 4260, 42610 - 42742, 42781 - 4279, 4340 - 4349, 4530 )	5,187	585	690	670	440	381	404	499	561	536	421	420
Other Diseases of the Gastrointestinal System (5200 - 5209, 52400 - 52419, 5371, 55000 - 55093, 55300 - 5539, 5602, 5609, 5651, 5692, 56981)	9,108	1015	1053	936	895	894	862	829	842	864	918	772
Other Diseases of the Genital and Urinary Systems (5933, 5935, 59382, 5961, 5962, 5989, 5991, 5996, 6190 - 6199)	424	33	33	46	40	48	48	47	40	49	40	35
Other Fetal/Placental Anomalies (6537, 6588)	7	2	1	2	0	1	0	0	1	0	0	2
Other Musculoskeletal System Diseases (7333)	45	9	4	9	1	6	6	1	4	2	3	2
Maternal Exposures Affecting Fetus (760)	3,969	345	513	575	433	394	344	324	304	369	368	263
Fetal Alcohol Syndrome (76071)	330	35	60	39	43	32	21	18	34	26	22	19
Other Maternal Exposures Affecting the Fetus (7600, 76071, 76075, 76079)	3,731	320	469	549	402	368	329	311	282	347	354	249
<b>One or More Reportable Diagnosis</b>	<b>87,994</b>	<b>9289</b>	<b>9385</b>	<b>9247</b>	<b>7887</b>	<b>7964</b>	<b>7961</b>	<b>7960</b>	<b>8700</b>	<b>9678</b>	<b>9923</b>	<b>9497</b>

Frequencies include all children reported with a birth defect who were born in Michigan and whose mother was a resident at the time of birth. This enables the calculation of birth defects incidence rates.

Columns do not add to diagnostic group totals nor column totals due to cases with multiple diagnosed conditions that cross diagnostic groupings.

Conditions are reportable if identified within the first two years of a child's life. The incidence frequencies in this table represent cases diagnosed within the first year of life.

Diagnoses are coded using the 9th Revision to the International Classification of Diseases - ICD 9 CM

Diagnostic Code Groupings used for congenital anomaly codes are as used by the Centers for Disease Control and Prevention.

The increased numbers of cases diagnosed with hearing deficiency in evidence since 1997 is related directly to a rapid increase in screening of Michigan newborns for hearing loss by birthing hospitals.

A change in ICD-9 CM coding added unique codes for hypospadias and epispadias in October of 1996. This is the cause of the discontinuity in the reported frequencies for these conditions as listed under the diagnostic grouping "H04 Hypospadias and Epispadias (75261, 75262)".

## Appendix F

**Table 2: Michigan Birth Defects Prevalence Rates by Diagnostic Group and by Birth Year**  
**Cases Diagnosed within One Year from Birth**  
**Michigan Resident Children Born in Michigan During 1992 through 2002**  
**Three Year Moving Average Prevalence Rates**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Birth Year Interval																	
	1992-1994		1993-1995		1994-1996		1995-1997		1996-1998		1997-1999		1998-2000		1999-2001		2000-2002	
	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.
Congenital Anomalies of the Central Nervous System (740-742)	29.8	1.65	28.7	1.64	26.7	1.60	26.7	1.61	26.5	1.60	29.5	1.69	31.8	1.75	34.7	1.83	35.5	1.85
Anencephalus (7400,7401)	0.9	0.29	1.0	0.30	0.8	0.28	0.7	0.27	0.7	0.26	0.9	0.29	1.1	0.33	1.0	0.31	1.1	0.32
Spina Bifida w/o Anencephaly ( 7410, 7419 w/o 7400, 7401)	4.1	0.61	4.4	0.64	4.1	0.63	4.2	0.64	3.9	0.61	3.9	0.61	3.8	0.60	4.3	0.64	4.0	0.62
Hydrocephalus w/o Spina Bifida (7423 w/o 7410, 7419)	9.4	0.93	8.6	0.90	7.8	0.86	7.6	0.86	7.6	0.86	8.7	0.92	9.2	0.95	10.2	0.99	9.9	0.98
Encephalocele (7420)	1.4	0.36	1.2	0.34	1.0	0.32	0.8	0.28	0.7	0.26	0.7	0.25	0.8	0.28	1.0	0.30	1.0	0.31
Microcephalus (7421)	6.1	0.75	6.2	0.76	6.4	0.78	6.1	0.77	5.7	0.74	6.4	0.79	7.5	0.85	8.4	0.90	8.9	0.93
All Other CNS Anomalies	12.7	1.08	12.0	1.06	11.1	1.03	11.6	1.06	11.8	1.07	13.6	1.15	14.1	1.17	15.4	1.22	16.1	1.25
Congenital Anomalies of the Eye (743)	18.7	1.31	18.3	1.31	17.3	1.28	17.7	1.31	19.4	1.37	22.2	1.47	25.4	1.57	26.4	1.60	26.8	1.61
Anaphthalmia/Microphthalmia (74300-74306, 74310-74312)	1.3	0.34	1.3	0.36	1.4	0.37	1.5	0.38	1.6	0.39	1.7	0.40	1.7	0.40	1.7	0.40	1.9	0.43
Congenital Cataract ( 74330 - 74334)	1.6	0.38	1.8	0.41	1.9	0.42	1.8	0.42	1.8	0.42	1.8	0.42	2.2	0.46	2.3	0.47	2.4	0.48
Aniridia (74345)	***	***	0.1	0.11	0.1	0.12	0.2	0.12	0.2	0.14	0.2	0.13	0.2	0.14	0.2	0.12	0.2	0.13
All Other Congenital Anomalies of the Eye	16.6	1.23	15.9	1.22	14.8	1.19	15.4	1.22	17.0	1.28	19.7	1.38	22.7	1.48	23.9	1.52	24.1	1.53
Congenital Anomalies of the Ear, Face and Neck (744)	18.7	1.31	17.7	1.29	15.8	1.23	14.6	1.19	13.6	1.15	13.8	1.15	14.0	1.16	15.0	1.20	15.9	1.24
Anotia/Microtia (74401,74423)	0.7	0.26	0.7	0.25	0.5	0.23	0.6	0.24	0.6	0.24	0.9	0.30	1.0	0.32	1.2	0.34	1.1	0.33
All Other Congenital Anomalies of the Ear, Face and Neck	18.4	1.30	17.4	1.28	15.6	1.22	14.3	1.18	13.4	1.14	13.4	1.14	13.6	1.15	14.6	1.19	15.5	1.23
Congenital Anomalies of the Heart and Circulatory System (745-746)	145.8	3.66	149.4	3.75	152.1	3.81	148.6	3.79	150.9	3.82	149.3	3.80	149.2	3.80	153.4	3.85	157.9	3.91
Common Truncus (7450)	1.2	0.33	1.1	0.31	1.0	0.31	1.1	0.33	1.4	0.36	1.4	0.37	1.2	0.35	1.2	0.34	1.1	0.33
Transposition of Great Arteries (74510, 74511, 74512, 74519)	4.7	0.66	4.4	0.64	4.3	0.64	4.2	0.64	4.6	0.67	4.6	0.67	4.9	0.69	4.8	0.68	5.1	0.70
Teralogy of Fallot (7452)	5.4	0.71	5.3	0.71	5.4	0.72	5.2	0.71	5.5	0.73	5.5	0.73	5.4	0.72	5.1	0.71	4.9	0.69
Ventricular Septal Defect (7454)	40.9	1.94	39.7	1.93	38.6	1.92	37.4	1.90	39.4	1.95	39.3	1.95	38.9	1.94	36.7	1.89	36.3	1.88

## Appendix F

**Table 2: Michigan Birth Defects Prevalence and Rates by Diagnostic Group and by Birth Year**  
**Cases Diagnosed within One Year from Birth**  
**Michigan Resident Children Born in Michigan During 1992 through 2002**  
**Three Year Moving Average Prevalence Rates**  
**(continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Birth Year Interval																	
	1992-1994		1993-1995		1994-1996		1995-1997		1996-1998		1997-1999		1998-2000		1999-2001		2000-2002	
	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.
Congenital Anomalies of the Heart/Circulatory System (continued)																		
Atrial Septal Defect (7455)	37.8	1.86	43.8	2.03	49.8	2.18	51.5	2.23	53.2	2.27	53.6	2.28	55.3	2.31	57.3	2.35	60.4	2.42
Endocardial Cushion Defect (74560, 74561, 74569)	3.7	0.58	3.7	0.59	4.1	0.63	4.3	0.65	4.4	0.65	4.2	0.64	3.9	0.61	3.9	0.61	4.0	0.62
Pulmonary Valve Atresia and Stenosis (74601, 74602)	10.2	0.97	9.9	0.96	10.2	0.98	9.9	0.98	10.6	1.01	11.0	1.03	10.8	1.02	11.2	1.04	10.3	1.00
Tricuspid Valve Atresia and Stenosis (7461)	1.2	0.33	1.1	0.32	1.1	0.33	1.2	0.34	1.2	0.34	1.2	0.35	1.4	0.37	1.8	0.42	2.0	0.44
Ebstein's Anomaly (7462)	0.7	0.26	0.6	0.23	0.5	0.21	0.7	0.25	0.8	0.28	1.2	0.33	1.8	0.42	2.7	0.51	3.0	0.54
Aortic Valve Stenosis (7463)	2.1	0.44	1.8	0.42	1.7	0.40	1.6	0.40	1.8	0.42	2.4	0.48	2.7	0.52	2.6	0.50	2.2	0.47
Hypoplastic Left Heart Syndrome (7467)	3.4	0.56	3.3	0.56	3.3	0.56	3.6	0.59	3.5	0.58	3.7	0.60	3.7	0.60	4.2	0.64	4.3	0.64
Patent Ductus Arteriosus (7470)	49.8	2.14	51.3	2.19	52.3	2.24	48.1	2.15	45.4	2.10	42.1	2.02	40.2	1.97	41.3	2.00	42.0	2.02
Coarctation of Aorta (74710)	4.4	0.64	4.3	0.64	4.7	0.67	4.9	0.69	5.5	0.73	5.9	0.75	6.5	0.79	6.3	0.78	6.1	0.77
Pulmonary Artery Anomalies (7473)	13.5	1.12	14.5	1.17	14.5	1.18	14.9	1.20	15.9	1.24	17.1	1.29	18.0	1.32	19.5	1.37	20.3	1.40
All Other Congenital Anomalies of the Heart and Circulatory	62.3	2.39	61.1	2.40	63.4	2.46	65.2	2.51	68.2	2.57	67.0	2.55	64.7	2.50	65.5	2.52	67.7	2.56
Congenital Anomalies of the Respiratory System (747 - 748)	30.2	1.67	27.6	1.61	25.4	1.56	23.0	1.49	24.3	1.53	27.2	1.62	32.3	1.77	38.0	1.92	41.7	2.01
Lung Agenesis/Hypoplasia (7485)	5.2	0.69	4.9	0.68	4.9	0.68	4.9	0.69	5.6	0.74	6.3	0.78	6.8	0.81	6.2	0.78	5.6	0.74
Choanal Atresia (7480)	1.4	0.36	1.2	0.34	1.2	0.34	1.3	0.36	1.5	0.38	1.5	0.38	1.6	0.39	1.7	0.40	1.9	0.42
All Other Congenital Anomalies of the Respiratory System	25.5	1.53	23.1	1.47	20.8	1.41	18.3	1.33	19.0	1.36	21.4	1.44	26.2	1.59	32.2	1.77	36.6	1.88
Cleft Palate and Cleft Lip (749)	14.4	1.15	13.6	1.13	13.7	1.14	14.6	1.19	15.0	1.20	15.8	1.24	15.5	1.22	15.6	1.23	14.7	1.19
Cleft Palate (74900 - 74904 w/o Cleft Lip 7491, 7492)	5.2	0.69	5.1	0.69	5.2	0.70	5.2	0.71	5.3	0.72	5.4	0.73	5.5	0.73	5.5	0.73	5.1	0.70
Cleft Lip w and w/o Cleft Palate (7491, 7492)	9.2	0.92	8.6	0.90	8.5	0.90	9.5	0.96	9.7	0.97	10.3	1.00	10.0	0.98	10.1	0.99	9.6	0.97

## Appendix F

**Table 2: Michigan Birth Defects Prevalence and Rates by Diagnostic Group and by Birth Year**  
**Cases Diagnosed within One Year from Birth**  
**Michigan Resident Children Born in Michigan During 1992 through 2002**  
**Three Year Moving Average Prevalence Rates**  
**(continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Birth Year Interval																	
	1992-1994		1993-1995		1994-1996		1995-1997		1996-1998		1997-1999		1998-2000		1999-2001		2000-2002	
	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.
Congenital Anomalies of the Upper Alimentary Canal/ Digestive (750-751)	50.2	2.15	48.3	2.13	46.2	2.10	46.0	2.11	47.3	2.14	47.0	2.13	47.3	2.14	48.1	2.16	47.6	2.15
Esophageal Atresia/Tracheoesophageal Fistula (7503)	4.8	0.66	5.2	0.70	3.4	0.57	3.4	0.57	3.0	0.54	3.2	0.55	2.9	0.53	3.0	0.54	2.8	0.52
Rectal and Large Intestinal Atresia/Stenosis (7512)	4.3	0.63	4.2	0.63	4.6	0.66	4.6	0.66	4.6	0.67	4.5	0.66	5.0	0.70	4.8	0.68	4.7	0.68
Pyloric Stenosis (7505)	18.9	1.32	16.9	1.26	16.9	1.27	17.3	1.29	18.9	1.35	19.4	1.37	18.7	1.35	19.1	1.36	18.6	1.34
Hirschsprung's Disease (congenital megacolon) (7513)	2.9	0.52	2.6	0.50	2.7	0.51	2.8	0.52	3.2	0.56	3.3	0.56	3.4	0.57	3.2	0.56	3.0	0.54
Biliary Atresia (75161)	1.3	0.35	1.5	0.37	1.4	0.37	1.4	0.37	1.3	0.36	1.2	0.34	1.3	0.36	1.3	0.35	1.1	0.32
Other Cong. Anomalies of Upper Alimentary Canal/ Digestive	21.0	1.39	21.1	1.41	20.5	1.40	19.9	1.39	19.8	1.38	18.7	1.34	19.4	1.37	19.8	1.39	20.3	1.40
Congenital Anomalies of the Genital and Urinary Systems (752 - 753)	105.2	3.11	105.7	3.15	102.1	3.12	94.0	3.01	87.8	2.92	90.3	2.96	101.4	3.13	110.8	3.27	114.4	3.33
Renal Agenesis/Hypoplasia (7530)	4.8	0.66	4.8	0.67	5.2	0.70	5.2	0.71	5.4	0.72	5.4	0.72	6.0	0.76	5.8	0.75	5.9	0.76
Bladder Exstrophy (7535)	0.5	0.20	0.5	0.21	0.5	0.21	0.4	0.20	0.4	0.18	0.3	0.16	0.3	0.16	0.4	0.19	0.5	0.21
Obstructive Genitourinary Defects (75320-75329, 7536)	14.5	1.15	14.8	1.18	16.0	1.24	16.7	1.27	16.3	1.25	16.5	1.26	17.4	1.30	19.4	1.37	20.8	1.42
Hypospadias and Epispadias (75261, 75262)	0.3	0.16	1.9	0.42	5.6	0.73	14.7	1.19	22.0	1.46	28.2	1.65	29.9	1.70	30.7	1.72	30.1	1.71
All Other Congenital Anomalies of the Genital and Urinary	105.2	3.11	105.7	3.15	102.1	3.12	94.0	3.01	87.8	2.92	90.3	2.96	101.4	3.13	110.8	3.27	114.4	3.33
Congenital Anomalies of the Musculoskeletal System (754 - 756)	142.1	3.61	131.6	3.52	122.9	3.43	116.9	3.36	117.6	3.37	122.6	3.44	133.5	3.59	147.4	3.78	156.6	3.89
Upper Limb Reduction Deformities (75520 - 75529)	3.2	0.54	2.5	0.49	2.3	0.47	2.3	0.47	2.2	0.46	2.3	0.47	2.4	0.48	2.5	0.49	2.5	0.49
Lower Limb Reduction Deformities (75530 - 75539)	1.4	0.36	1.4	0.37	1.6	0.39	1.4	0.37	1.3	0.35	1.3	0.35	1.4	0.37	1.7	0.40	1.7	0.41
Gastroschisis/Omphalocele (7567)	5.2	0.69	5.6	0.73	5.7	0.74	4.8	0.68	4.1	0.63	2.9	0.53	2.4	0.48	2.3	0.47	2.0	0.44
Congenital Hip Dislocation (75430, 75431, 75435)	16.1	1.22	14.8	1.18	14.1	1.16	13.1	1.13	12.6	1.11	12.3	1.09	12.9	1.12	13.7	1.15	14.3	1.18
Diaphragmatic Hernia (7566)	3.1	0.54	2.9	0.52	3.0	0.53	2.9	0.53	2.9	0.53	3.0	0.54	3.0	0.54	3.2	0.55	2.8	0.52
All Other Congenital Anomalies of the Musculoskeletal System	119.6	3.31	110.9	3.23	103.0	3.14	98.6	3.09	100.1	3.11	106.1	3.20	116.8	3.36	130.9	3.56	141.2	3.70

Appendix F

**Table 2: Michigan Birth Defects Prevalence and Rates by Diagnostic Group and by Birth Year**  
**Cases Diagnosed within One Year from Birth**  
**Michigan Resident Children Born in Michigan During 1992 through 2002**  
**Three Year Moving Average Prevalence Rates**  
**(continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Birth Year Interval																	
	1992-1994		1993-1995		1994-1996		1995-1997		1996-1998		1997-1999		1998-2000		1999-2001		2000-2002	
	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.
Congenital Anomalies of the Integument (757)	29.7	1.65	28.4	1.63	27.3	1.62	24.7	1.55	22.8	1.48	21.8	1.45	21.3	1.43	22.2	1.47	21.9	1.46
Chromosomal Anomalies (758)	20.8	1.38	19.2	1.34	19.0	1.35	18.3	1.33	18.4	1.34	19.0	1.36	20.3	1.40	21.7	1.45	21.1	1.43
Trisomy 13 (7581)	1.4	0.35	1.1	0.33	0.9	0.29	1.0	0.31	1.0	0.30	1.0	0.31	1.0	0.30	1.0	0.30	0.9	0.29
Down Syndrome (7580)	11.5	1.03	10.7	1.00	10.6	1.01	10.2	0.99	10.4	1.00	10.7	1.02	11.0	1.03	11.9	1.08	12.2	1.09
Trisomy 18 (7582)	1.4	0.35	1.3	0.35	1.2	0.34	1.2	0.33	1.1	0.33	1.4	0.36	1.4	0.37	1.5	0.38	1.3	0.36
All Other Chromosomal Anomalies	7.2	0.81	6.7	0.79	6.8	0.81	6.5	0.79	6.6	0.80	6.9	0.82	8.1	0.89	8.6	0.91	8.1	0.88
Other and Unspecified Congenital Anomalies (759)	20.9	1.39	16.5	1.24	14.1	1.16	14.7	1.19	17.8	1.31	22.5	1.48	30.4	1.72	40.9	1.99	46.9	2.13
Infectious Conditions Occurring in the Perinatal Period (0900 - 0909, 7710 - 7712)	14.5	1.15	12.9	1.10	9.8	0.97	8.8	0.92	8.8	0.92	9.8	0.97	10.4	1.00	11.4	1.05	12.1	1.08
Syphilis (0900-0909)	9.2	0.92	6.7	0.79	3.9	0.61	3.1	0.55	3.1	0.55	2.7	0.51	2.0	0.44	1.5	0.38	1.4	0.37
Other Infections (7710 - 7712)	5.4	0.71	6.2	0.76	5.9	0.75	5.7	0.74	5.7	0.74	7.1	0.83	8.4	0.90	10.0	0.98	10.7	1.02
Familial/Congenital Neoplasms (23770 - 23772)	0.7	0.26	0.8	0.27	0.7	0.26	0.7	0.26	0.8	0.27	0.9	0.29	1.0	0.31	1.0	0.32	1.0	0.31
Endocrine/Metabolic Disorders (243, 2521, 2532, 2538, 2552, 2558, 2578, 2594, 2700 - 2739, 2753, 2770 - 2779, 27911, 2792)	20.4	1.37	21.0	1.40	21.4	1.43	21.2	1.43	22.8	1.48	25.6	1.57	30.2	1.71	32.5	1.77	31.9	1.76
Diseases of the Blood and Blood Forming Organs (2820 - 2829, 2840, 2860 - 2869, 2873)	14.6	1.16	15.6	1.21	15.1	1.20	14.3	1.18	13.4	1.14	14.0	1.16	15.5	1.23	15.9	1.24	16.0	1.24

## Appendix F

**Table 2: Michigan Birth Defects Prevalence and Rates by Diagnostic Group and by Birth Year**  
**Cases Diagnosed within One Year from Birth**  
**Michigan Resident Children Born in Michigan During 1992 through 2002**  
**Three Year Moving Average Prevalence Rates**  
**(continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Birth Year Interval																	
	1992-1994		1993-1995		1994-1996		1995-1997		1996-1998		1997-1999		1998-2000		1999-2001		2000-2002	
	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.
Other Diseases of the Central and Peripheral Nervous System (3301, 3317, 33189, __3319, 3341, 3342, 3350, 3379, 3430 - 3439, 3456, 3480, 3526, 3560 - 3569, 3580 - __3599)	12.6	1.07	12.5	1.08	12.5	1.09	12.2	1.08	12.6	1.10	14.3	1.18	16.4	1.26	17.5	1.30	16.7	1.27
Other Diseases of the Eye (36260 - 36266, 36320, 36900 - 3699, 37716, 3780 - __3789, 37950 - 37959)	31.2	1.69	35.9	1.84	38.5	1.92	39.3	1.95	40.0	1.97	42.9	2.04	45.5	2.10	48.1	2.16	45.9	2.11
Hearing Deficiency (3899)	2.0	0.43	2.0	0.43	2.2	0.46	3.0	0.54	4.9	0.69	8.1	0.88	13.5	1.14	18.8	1.35	22.5	1.48
Other Diseases of the Heart and Circulatory System (4250 - 4254, 4260, 42610 - __42742, 42781 - 4279, 4340 - 4349, 4530 )	46.5	2.07	44.0	2.03	37.1	1.88	30.8	1.73	32.4	1.77	36.9	1.89	40.2	1.97	38.2	1.92	34.7	1.83
Other Diseases of the Gastrointestinal System (5200 - 5209, 52400 - 52419, 5371, 55000 - 55093, 55300 - 5539, 5602, 5609, 5651, 5692, 56981)	71.8	2.57	70.5	2.57	67.8	2.55	66.7	2.54	65.2	2.51	63.8	2.49	63.9	2.49	66.1	2.53	64.3	2.50
Other Diseases of the Genital and Urinary Systems (5933, 5935, 59382, 5961, 5962, 5989, 5991, 5996, 6190 - 6199)	2.7	0.50	2.9	0.52	3.3	0.56	3.4	0.57	3.6	0.59	3.4	0.57	3.4	0.58	3.2	0.56	3.1	0.55
Other Fetal/Placental Anomalies (6537, 6588)	0.1	0.10	***	***	***	***	***	***	***	***	***	***	***	***	***	***	***	***
Other Musculoskeletal System Diseases (7333)	0.5	0.22	0.3	0.18	0.4	0.20	0.3	0.18	0.3	0.18	0.3	0.16	0.2	0.13	0.2	0.15	0.2	0.13
Maternal Exposures Affecting Fetus (760)	34.2	1.77	37.2	1.87	34.9	1.83	29.4	1.69	26.8	1.61	24.5	1.54	25.1	1.56	26.2	1.59	25.2	1.56
Fetal Alcohol Syndrome (76071)	3.2	0.54	3.5	0.57	2.8	0.52	2.4	0.48	1.8	0.42	1.8	0.42	2.0	0.44	2.1	0.45	1.7	0.40
Other Maternal Exposures Affecting the Fetus (7600, 76071, 76075, 76079)	32.0	1.71	34.7	1.81	32.8	1.77	27.6	1.63	25.4	1.57	23.2	1.50	23.7	1.51	24.8	1.55	23.9	1.52

**Table 2: Michigan Birth Defects Prevalence and Rates by Diagnostic Group and by Birth Year**  
**Cases Diagnosed within One Year from Birth**  
**Michigan Resident Children Born in Michigan During 1992 through 2002**  
**Three Year Moving Average Prevalence Rates**  
**(continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Birth Year Interval																	
	1992-1994		1993-1995		1994-1996		1995-1997		1996-1998		1997-1999		1998-2000		1999-2001		2000-2002	
	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.	Case Rate	C.I.
One or More Reportable Diagnosis	667.1	7.82	648.5	7.80	624.4	7.73	598.8	7.61	602.1	7.64	620.3	7.75	663.5	8.01	713.0	8.31	733.1	8.42

Rates are not calculated if fewer than 5 events. \*\*\* denotes too few events.

Rates Per 10,000 Michigan Born Resident Live Births

Rates include all children reported with a birth defect who were born in Michigan and whose mother was a resident at the time of birth. This enables the calculation of birth defects incidence rates.

Confidence intervals for each rate are provided to estimate the variability that can be expected for any specific rate due to chance alone. The true rate lies between the lower and upper bounds of the interval with 95% statistical confidence.

Columns do not add to diagnostic group totals nor column totals due to cases with multiple diagnosed conditions that cross diagnostic groupings.

Conditions are reportable if identified within the first two years of a child's life. The incidence frequencies in this table represent cases diagnosed within the first year of life.

Diagnoses are coded using the 9th Revision to the International Classification of Diseases - ICD 9 CM

Diagnostic Code Groupings used for congenital anomaly codes are as used by the Centers for Disease Control and Prevention

The increased numbers of cases diagnosed with hearing deficiency in evidence since 1997 is related directly to a rapid increase in screening of Michigan newborns for hearing loss by birthing hospitals

A change in ICD-9 CM coding added unique codes for hypospadias and epispadias in October of 1996. This is the cause of the discontinuity in the reported frequencies for these conditions as listed under the diagnostic grouping "H04 Hypospadias and Epispadias (75261, 75262)"

# Appendix F

**Table 3: Infant Deaths to Michigan Children with Reported Birth Defects and Mortality Rates  
by Diagnostic Group and by Birth Year  
Cases Diagnosed within One Year from Birth  
Michigan Resident Children Born in Michigan During 1992 through 2002  
Moving Three Year Mortality Numbers**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Number of Deaths by Birth Year Interval								
	1992-1994	1993-1995	1994-1996	1995-1997	1996-1998	1997-1999	1998-2000	1999-2001	2000-2002
<b>Congenital Anomalies</b>									
Congenital Anomalies of the Central Nervous System (740-742)	210	176	152	149	156	176	159	166	162
Congenital Anomalies of the Eye (743)	24	25	27	24	21	23	21	24	31
Congenital Anomalies of the Ear, Face and Neck (744)	39	27	21	25	31	31	24	23	27
Congenital Anomalies of the Heart and Circulatory System (745-746)	571	539	517	512	517	518	497	500	502
Congenital Anomalies of the Respiratory System (747 - 748)	224	213	200	178	190	220	242	218	201
Cleft Palate and Cleft Lip (749)	46	38	42	36	33	32	29	28	32
Congenital Anomalies of the Upper Alimentary Canal/ Digestive System (750-751)	97	94	88	88	93	92	88	81	83
Congenital Anomalies of the Genital and Urinary Systems (752 - 753)	214	194	174	166	156	160	159	158	170
Congenital Anomalies of the Musculoskeletal System (754 - 756)	251	228	210	199	178	170	170	185	181
Congenital Anomalies of the Integument (757)	22	25	19	16	11	10	13	19	20
Chromosomal Anomalies (758)	154	119	118	118	127	136	155	160	147
Other and Unspecified Congenital Anomalies (759)	125	106	99	101	124	138	150	152	152

# Appendix F

**Table 3: Infant Deaths to Michigan Children with Reported Birth Defects and Mortality Rates  
by Diagnostic Group and by Birth Year  
Cases Diagnosed within One Year from Birth  
Michigan Resident Children Born in Michigan During 1992 through 2002  
Moving Three Year Mortality Numbers (continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Number of Deaths by Birth Year Interval								
	1992-1994	1993-1995	1994-1996	1995-1997	1996-1998	1997-1999	1998-2000	1999-2001	2000-2002
<b>Other Reportable Conditions</b>									
Infectious Conditions Occurring in the Perinatal Period (0900 - 0909, 7710 - 7712)	35	31	25	24	26	30	37	51	57
Familial/Congenital Neoplasms (23770 - 23772)	5	6	7	7	6	3	1	2	3
Endocrine/Metabolic Disorders (243, 2521, 2532, 2538, 2552, 2558, 2578, 2594, 2700 - 2739, 2753, 2770 - 2779, 27911, 2792)	63	67	69	68	66	60	59	68	75
Diseases of the Blood and Blood Forming Organs (2820 - 2829, 2840, 2860 - 2869, 2873)	51	59	55	55	54	62	63	58	46
Other Diseases of the Central and Peripheral Nervous System (3301, 3317, 33189, 3319, 3341, 3342, 3350, 3379, 3430 - 3439, 3456, 3480, 3526, 3560 - 3569, 3580 - 3599)	51	43	37	34	40	41	37	28	27
Other Diseases of the Eye (36260 - 36266, 36320, 36900 - 3699, 37716, 3780 - 3789, 37950 - 37959)	52	49	41	42	48	50	55	61	65
Hearing Deficiency (3899)	3	5	4	4	3	3	4	6	11
Other Diseases of the Heart and Circulatory System (4250 - 4254, 4260, 42610 - 42742, 42781 - 4279, 4340 - 4349, 4530 )	168	152	127	100	98	117	140	137	120
Other Diseases of the Gastrointestinal System (5200 - 5209, 52400 - 52419, 5371, 55000 - 55093, 55300 - 5539, 5602, 5609, 5651, 5692, 56981)	145	130	107	107	110	115	101	96	98

## Appendix F

**Table 3: Infant Deaths to Michigan Children with Reported Birth Defects and Mortality Rates  
by Diagnostic Group and by Birth Year  
Cases Diagnosed within One Year from Birth  
Michigan Resident Children Born in Michigan During 1992 through 2002  
Moving Three Year Mortality Numbers (continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Number of Deaths by Birth Year Interval								
	1992-1994	1993-1995	1994-1996	1995-1997	1996-1998	1997-1999	1998-2000	1999-2001	2000-2002
<b>Other Reportable Conditions (continued)</b>									
Other Diseases of the Genital and Urinary Systems (5933, 5935, 59382, 5961, 5962, 5989, 5991, 5996, 6190 - 6199)	4	3	3	1	1	1	1	1	1
Other Fetal/Placental Anomalies (6537, 6588)	1	0	0	0	0	0	0	0	0
Other Musculoskeletal System Diseases (7333)	0	0	0	0	0	0	0	0	0
Maternal Exposures Affecting Fetus (760)	63	48	44	27	27	27	32	36	32
<b>One or More Reportable Diagnosis</b>	<b>1347</b>	<b>1248</b>	<b>1162</b>	<b>1126</b>	<b>1144</b>	<b>1179</b>	<b>1186</b>	<b>1187</b>	<b>1185</b>

Infant Deaths Are Deaths Before the First Birthday

Frequencies include all children reported with a birth defect who were born in Michigan and whose mother was a resident at the time of birth. This enables the calculation of birth defects incidence rates.

Columns do not add to diagnostic group totals nor column totals due to cases with multiple diagnosed conditions that cross diagnostic groupings.

Conditions are reportable if identified within the first two years of a child's life. The incidence frequencies in this table represent cases diagnosed within the first year of life.

Diagnoses are coded using the 9th Revision to the International Classification of Diseases - ICD 9 CM

Diagnostic Code Groupings used for congenital anomaly codes are as used by the Centers for Disease Control and Prevention

# Appendix F

**Table 4: Infant Death Rates to Michigan Children with Reported Birth Defects and Mortality Rates  
by Diagnostic Group and by Birth Year  
Cases Diagnosed within One Year from Birth  
Michigan Resident Children Born in Michigan During 1992 through 2002  
Moving Three Year Mortality Numbers**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Number of Deaths by Birth Year Interval								
	1992-1994	1993-1995	1994-1996	1995-1997	1996-1998	1997-1999	1998-2000	1999-2001	2000-2002
<b>Congenital Anomalies</b>									
Congenital Anomalies of the Central Nervous System (740-742)	168.4	149.8	141.4	140.2	176.0	150.6	126.0	120.5	114.9
Congenital Anomalies of the Eye (743)	30.6	33.5	38.9	34.2	23.0	26.1	20.9	22.9	29.2
Congenital Anomalies of the Ear, Face and Neck (744)	49.9	37.4	33.0	43.1	31.0	56.7	43.2	38.7	42.8
Congenital Anomalies of the Heart and Circulatory System (745-746)	93.6	88.2	84.6	86.6	518.0	87.4	83.9	82.1	80.1
Congenital Anomalies of the Respiratory System (747 - 748)	176.9	189.0	195.9	194.5	220.0	204.1	188.8	144.7	121.5
Cleft Palate and Cleft Lip (749)	76.4	68.2	76.2	61.9	32.0	51.1	47.2	45.2	54.8
Congenital Anomalies of the Upper Alimentary Canal/ Digestive System (750-751)	46.2	47.6	47.4	48.1	92.0	49.3	46.9	42.4	43.9
Congenital Anomalies of the Genital and Urinary Systems (752 - 753)	48.6	44.9	42.4	44.4	160.0	44.6	39.5	35.9	37.4
Congenital Anomalies of the Musculoskeletal System (754 - 756)	42.2	42.4	42.5	42.8	170.0	34.9	32.1	31.6	29.1
Congenital Anomalies of the Integument (757)	17.7	21.5	17.3	16.3	10.0	11.5	15.4	21.6	23.0
Chromosomal Anomalies (758)	176.6	151.2	154.5	162.1	136.0	179.9	192.1	185.4	175.6
Other and Unspecified Congenital Anomalies (759)	142.7	157.5	174.3	172.9	138.0	154.2	124.3	93.6	81.7

# Appendix F

**Table 4: Infant Death Rates to Michigan Children with Reported Birth Defects and Mortality Rates  
by Diagnostic Group and by Birth Year  
Cases Diagnosed within One Year from Birth  
Michigan Resident Children Born in Michigan During 1992 through 2002  
Moving Three Year Mortality Numbers (continued)**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Number of Deaths by Birth Year Interval								
	1992-1994	1993-1995	1994-1996	1995-1997	1996-1998	1997-1999	1998-2000	1999-2001	2000-2002
<b>Other Reportable Conditions</b>									
Infectious Conditions Occurring in the Perinatal Period (0900 - 0909, 7710 - 7712)	57.7	58.9	63.6	68.8	30.0	77.1	89.4	112.3	118.3
Familial/Congenital Neoplasms (23770 - 23772)	166.7	187.5	250.0	259.3	3.0	***	***	***	***
Endocrine/Metabolic Disorders (243, 2521, 2532, 2538, 2552, 2558, 2578, 2594, 2700 - 2739, 2753, 2770 - 2779, 27911, 2792)	73.7	78.2	80.1	80.5	60.0	59.1	49.2	52.7	59.1
Diseases of the Blood and Blood Forming Organs (2820 - 2829, 2840, 2860 - 2869, 2873)	83.3	92.6	90.8	96.7	62.0	111.9	102.1	91.9	72.4
Other Diseases of the Central and Peripheral Nervous System (3301, 3317, 33189, 3319, 3341, 3342, 3350, 3379, 3430 - 3439, 3456, 3480, 3526, 3560 - 3569, 3580 - 3599)	97.0	84.0	73.4	70.2	41.0	72.3	56.9	40.3	40.7
Other Diseases of the Eye (36260 - 36266, 36320, 36900 - 3699, 37716, 3780 - 3789, 37950 - 37959)	39.8	33.4	26.5	26.9	50.0	29.4	30.5	31.9	35.7
Hearing Deficiency (3899)	***	61.0	***	***	***	***	***	8.0	12.3
Other Diseases of the Heart and Circulatory System (4250 - 4254, 4260, 42610 - 42742, 42781 - 4279, 4340 - 4349, 4530 )	86.4	84.4	85.2	81.6	117.0	79.9	87.7	90.3	87.1
Other Diseases of the Gastrointestinal System (5200 - 5209, 52400 - 52419, 5371, 55000 - 55093, 55300 - 5539, 5602, 5609, 5651, 5692, 56981)	48.3	45.1	39.3	40.4	115.0	45.4	39.8	36.6	38.4

## Appendix F

**Table 4: Infant Death Rates to Michigan Children with Reported Birth Defects and Mortality Rates  
by Diagnostic Group and by Birth Year  
Cases Diagnosed within One Year from Birth  
Michigan Resident Children Born in Michigan During 1992 through 2002  
Moving Three Year Mortality Numbers**

Diagnostic Grouping (ICD-9 CM Diagnostic Code)	Number of Deaths by Birth Year Interval								
	1992-1994	1993-1995	1994-1996	1995-1997	1996-1998	1997-1999	1998-2000	1999-2001	2000-2002
<b>Other Reportable Conditions (continued)</b>									
Other Diseases of the Genital and Urinary Systems (5933, 5935, 59382, 5961, 5962, 5989, 5991, 5996, 6190 - 6199)	***	***	***	***	***	***	***	***	***
	***	***	***	***	***	***	***	***	***
Other Fetal/Placental Anomalies (6537, 6588)	***	***	***	***	***	***	***	***	***
	***	***	***	***	***	***	***	***	***
Other Musculoskeletal System Diseases (7333)	***	***	***	***	***	***	***	***	***
	***	***	***	***	***	***	***	***	***
Maternal Exposures Affecting Fetus (760)	44.0	31.6	31.4	23.1	27.0	27.8	32.1	34.6	32.0
<b>One or More Reportable Diagnosis</b>	48.2	47.1	46.3	47.3	43.4	47.9	45.0	41.9	40.7

Rates are deaths per 1,000 children from the birth interval with the specific diagnostic condition reported

Infant Deaths Are Deaths Before the First Birthday

Frequencies include all children reported with a birth defect who were born in Michigan and whose mother was a resident at the time of birth. This enables the calculation of birth defects incidence rates.

Columns do not add to diagnostic group totals nor column totals due to cases with multiple diagnosed conditions that cross diagnostic groupings.

Conditions are reportable if identified within the first two years of a child's life. The incidence frequencies in this table represent cases diagnosed within the first year of life.

Diagnoses are coded using the 9th Revision to the International Classification of Diseases - ICD 9 CM

Diagnostic Code Groupings used for congenital anomaly codes are as used by the Centers for Disease Control and Prevention

## Mapping of Birth Defects by County

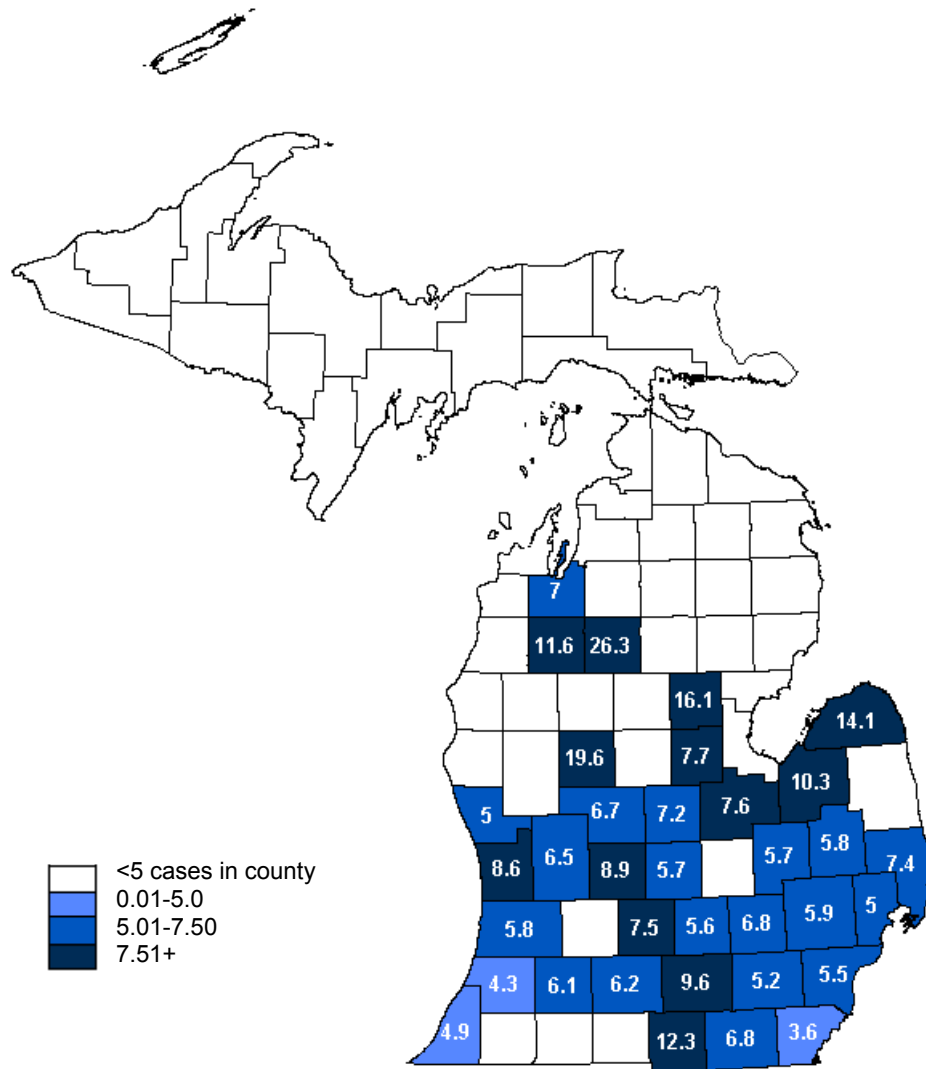


Figure 1: Prevalence of **neural tube defects** by county in Michigan between 1992-2002. The state average is 6.1 per 10,000. All prevalence rates are calculated as cases per 10,000 live births.

## Mapping of Birth Defects by County

Table 1: Prevalence of **neural tube defects** by county in Michigan between 1992-2002.  
Only counties with five or more cases were included.

County	Number of cases	Total Live Births	Rate	Neural Tube Defects	
				Lower Confidence Interval	Upper Confidence Interval
Allegan	9	15644	5.8	2.6	10.9
Berrien	12	24517	4.9	2.5	8.5
Calhoun	13	20856	6.2	3.3	10.7
Clinton	5	8793	5.7	1.8	13.3
Eaton	10	13421	7.5	3.6	13.7
Genesee	41	71897	5.7	4.1	7.7
Gladwin	5	3098	16.1	5.2	37.7
Grand Traverse	7	10061	7.0	2.8	14.3
Hillsdale	8	6523	12.3	5.3	24.2
Huron	6	4257	14.1	5.2	30.7
Ingham	24	42708	5.6	3.6	8.4
Ionia	8	9024	8.9	3.8	17.5
Jackson	22	22839	9.6	6.0	14.6
Kalamazoo	21	34601	6.1	3.8	9.3
Kent	65	100042	6.5	5.0	8.3
Lapeer	7	11982	5.8	2.3	12.0
Lenawee	9	13148	6.8	3.1	13.0
Livingston	14	20483	6.8	3.7	11.5
Macomb	54	108954	5.0	3.7	6.5
Manistee	6	2679	22.4	8.2	48.7
Mecosta	10	5092	19.6	9.4	36.1
Midland	9	11618	7.7	3.5	14.7
Missaukee	5	1899	26.3	8.5	61.4
Monroe	7	19263	3.6	1.5	7.5
Montcalm	6	9007	6.7	2.4	14.5
Muskegon	13	26081	5.0	2.7	8.5
Oakland	103	176176	5.8	4.8	7.1
Ottawa	32	37407	8.6	5.9	12.1
Saginaw	25	32699	7.6	4.9	11.3
St. Clair	17	22884	7.4	4.3	11.9
Tuscola	8	7786	10.3	4.4	20.2
Van Buren	5	11659	4.3	1.4	10.0
Washtenaw	23	44127	5.2	3.3	7.8
Wayne	198	357544	5.5	4.8	6.4
Wexford	5	4317	11.6	3.8	27.0

## Mapping of Birth Defects by County

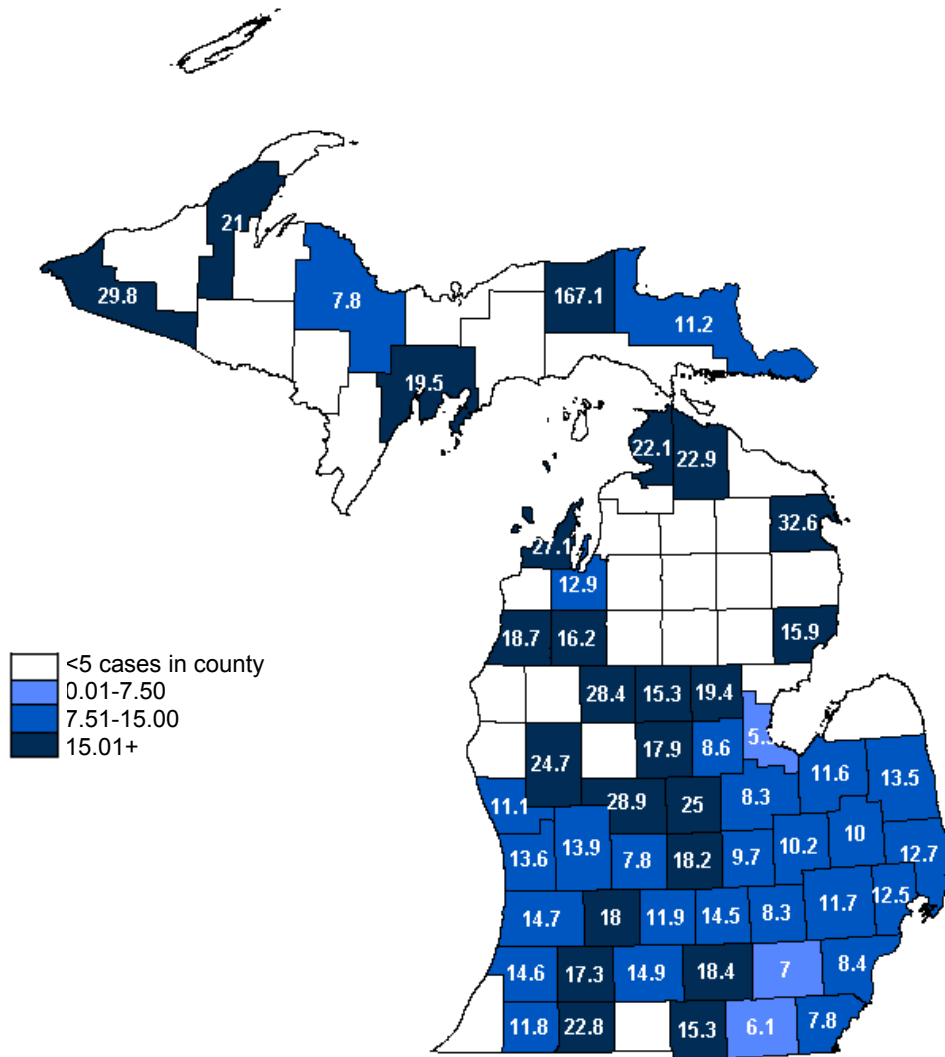


Figure 2: Prevalence of **orofacial clefts** by county in Michigan between 1992-2002. The state average is 11.8 per 10,000. All prevalence rates are calculated as cases per 10,000 live births.

## Mapping of Birth Defects by County

Table 2: Prevalence of **orofacial clefts** by county in Michigan between 1992-2002.  
Only counties with five or more cases were included.

Orofacial Clefts					
County	Number of cases	Total Live Births	Rate	Lower Confidence Interval	Upper Confidence Interval
Allegan	23	15644	14.7	9.3	22.1
Alpena	12	3685	32.6	16.8	56.9
Barry	14	7761	18.0	9.9	30.3
Bay	8	15032	5.3	2.3	10.5
Berrien	24	24517	9.8	6.3	14.6
Branch	15	6038	24.8	13.9	41.0
Calhoun	31	20856	14.9	10.1	21.1
Cass	7	5938	11.8	4.7	24.3
Cheboygan	7	3058	22.9	9.2	47.2
Chippewa	5	4462	11.2	3.6	26.2
Clare	6	3921	15.3	5.6	33.3
Clinton	16	8793	18.2	10.4	29.5
Delta	9	4608	19.5	8.9	37.1
Eaton	16	13421	11.9	6.8	19.4
Emmet	9	4065	22.1	10.1	42.0
Genesee	73	71897	10.2	10.1	10.9
Gladwin	6	3098	19.4	7.1	42.2
Gogebic	5	1677	29.8	9.7	69.6
Grand Traverse	13	10061	12.9	6.9	22.1
Gratiot	14	5592	25.0	13.7	42.0
Hillsdale	10	6523	15.3	7.4	28.2
Houghton	9	4295	21.0	9.6	39.8
Huron	8	4257	18.8	8.1	37.0
Ingham	62	42708	14.5	11.1	18.6
Ionia	7	9024	7.8	3.1	16.0
Iosco	5	3149	15.9	5.2	37.1
Isabella	13	7277	17.9	9.5	30.5
Jackson	42	22839	18.4	13.3	24.9
Kalamazoo	60	34601	17.3	13.2	22.3
Kent	139	100042	13.9	11.7	16.4
Lapeer	12	11982	10.0	5.2	17.5
Leelanau	6	2215	27.1	9.9	59.0
Lenawee	8	13148	6.1	2.6	12.0
Livingston	17	20483	8.3	4.8	13.3
Luce	12	718	167.1	86.4	291.9
Macomb	136	108954	12.5	10.5	14.8
Manistee	5	2679	18.7	6.1	43.6
Marquette	6	7697	7.8	2.9	17.0
Mecosta	11	5092	21.6	10.8	38.7
Midland	10	11618	8.6	4.1	15.8
Monroe	15	19263	7.8	4.4	12.8
Montcalm	26	9007	28.9	18.9	42.3
Muskegon	29	26081	11.1	7.4	16.0
Newaygo	17	6887	24.7	14.4	39.5
Oakland	206	176176	11.7	10.2	13.4
Osceola	9	3167	28.4	13.0	53.9
Ottawa	51	37407	13.6	10.2	17.9
Saginaw	27	32699	8.3	5.4	12.0
Sanilac	8	5931	13.5	5.8	26.6
Shiawassee	10	10315	11.6	6.0	20.3
St. Clair	29	22884	10.5	8.5	18.2
St. Joseph	22	9643	29.0	14.3	34.5
Tuscola	9	7786	11.6	12.7	35.0
Van Buren	17	11659	14.6	8.5	23.3
Washtenaw	31	44127	7.0	4.8	10.0
Wayne	300	357,544	8.4	7.5	9.4
Wexford	7	4,317	16.2	6.5	33.4

## Mapping of Birth Defects by County

## Mapping of Birth Defects by County

Table 3: Prevalence of **Down syndrome** by county in Michigan between 1992-2002.  
Only counties with five or more cases were included.

County	Number of cases	Down Syndrome		Lower Confidence Interval	Upper Confidence Interval
		Total Live Births	Rate		
Allegan	12	15644	7.7	4.0	13.4
Barry	9	7761	11.6	5.3	22.0
Bay	16	15032	10.6	6.1	17.3
Berrien	11	24517	4.5	2.2	8.0
Calhoun	14	20856	6.7	3.7	11.3
Clinton	6	8793	6.8	2.5	14.9
Delta	6	4608	13.0	4.8	28.3
Eaton	6	13421	4.5	1.6	9.7
Genesee	46	71897	6.4	4.7	8.5
Gladwin	5	3098	16.1	5.2	37.7
Grand Traverse	15	10061	14.9	8.3	24.6
Ingham	25	42708	5.9	3.8	8.6
Ionia	5	9024	5.5	1.8	12.9
Jackson	12	22839	5.3	2.7	9.2
Kalamazoo	35	34601	10.1	7.0	14.1
Kent	105	100042	10.5	8.6	12.7
Lapeer	10	11982	8.3	4.0	15.3
Lenawee	9	13148	6.8	3.1	13.0
Livingston	19	20483	9.3	5.6	14.5
Macomb	65	108954	6.0	4.6	7.6
Marquette	5	7697	6.5	2.1	15.2
Mecosta	5	5092	9.8	3.2	22.9
Midland	11	11618	9.5	5.3	18.0
Monroe	7	19263	3.6	1.5	7.5
Montcalm	13	9007	14.4	7.7	24.7
Muskegon	15	26081	5.8	3.2	9.5
Newaygo	5	6887	7.3	2.4	16.9
Oakland	118	176176	6.7	5.5	8.0
Ottawa	34	37407	9.1	6.3	12.7
Saginaw	21	32699	6.4	4.0	9.8
Shiawassee	11	10315	10.7	5.3	19.1
St. Clair	16	22884	7.0	4.0	11.4
St. Joseph	5	9643	5.2	1.7	12.1
Tuscola	8	7786	10.3	4.4	20.2
Van Buren	9	11659	7.7	3.5	14.7
Washtenaw	23	44127	5.2	3.3	7.8
Wayne	260	357,544	7.3	6.4	8.2
Wexford	5	4,317	11.6	3.8	27.0

## Mapping of Birth Defects by County

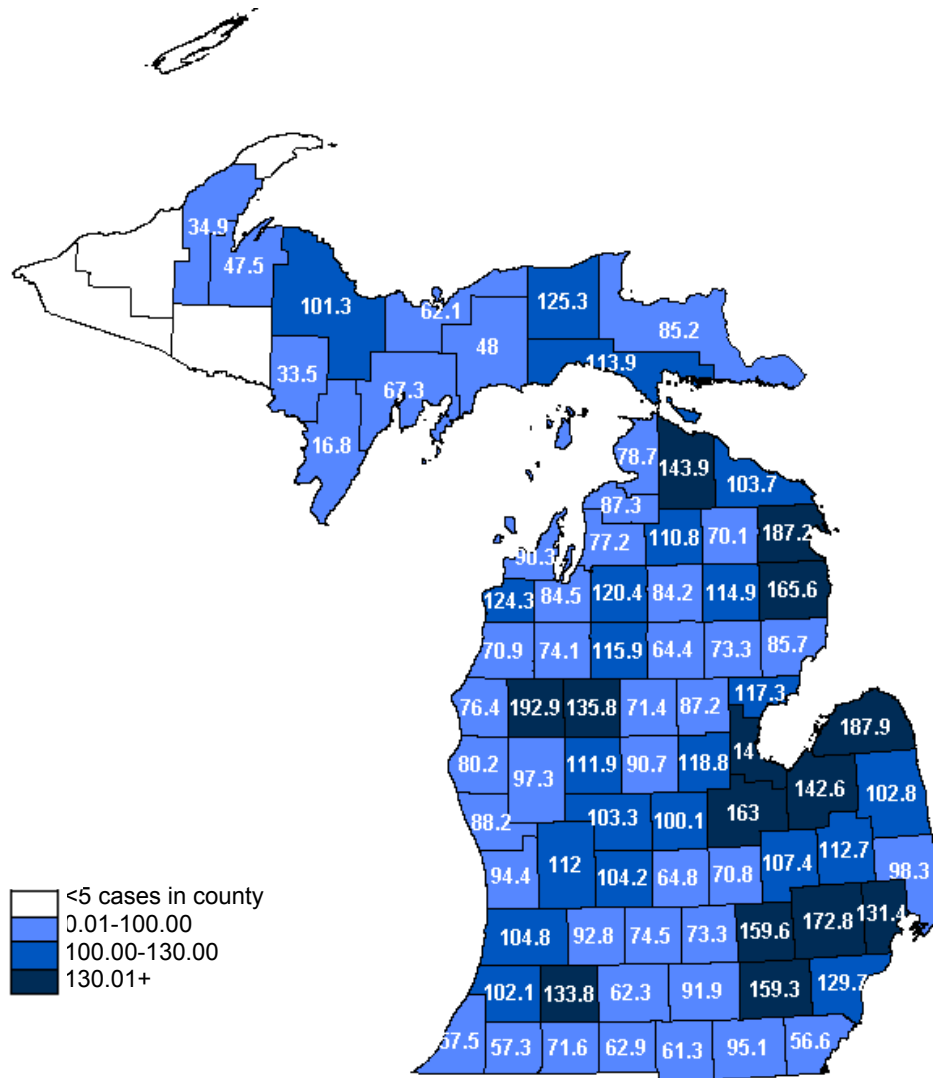


Figure 4: Prevalence of **congenital heart defects** by county in Michigan between 1992-2002. The state average is 119.7 per 10,000. All prevalence rates are calculated as cases per 10,000 live births.

## Mapping of Birth Defects by County

Table 4: Prevalence of **congenital heart defects** by county in Michigan between 1992-2002.  
Only counties with five or more cases were included.

County	Number of cases	Total Live Births	Rate	Congenital Heart Defects	
				Lower Confidence Interval	Upper Confidence Interval
Alcona	16	966	165.6	94.7	269.0
Alger	6	966	62.1	22.8	135.2
Allegan	164	15644	104.8	89.4	122.2
Alpena	69	3685	187.2	145.7	237.0
Antrim	21	2721	77.2	47.8	118.0
Arenac	23	1960	117.3	74.4	176.1
Baraga	5	1053	47.5	15.4	110.8
Barry	72	7761	92.8	72.6	116.8
Bay	212	15032	141.0	122.7	161.3
Benzie	24	1931	124.3	79.6	184.9
Berrien	141	24517	57.5	48.4	67.8
Branch	38	6038	62.9	44.5	86.4
Calhoun	130	20856	62.3	52.1	74.0
Cass	34	5938	57.3	39.6	80.0
Charlevoix	30	3438	87.3	58.9	124.6
Cheboygan	44	3058	143.9	104.5	193.2
Chippewa	38	4462	85.2	60.3	116.9
Clare	28	3921	71.4	47.4	103.2
Clinton	57	8793	64.8	49.1	84.0
Crawford	14	1662	84.2	46.1	141.3
Delta	31	4608	67.3	45.7	95.5
Dickinson	11	3279	33.5	16.7	60.0
Eaton	100	13421	74.5	60.6	90.6
Emmet	32	4065	78.7	53.8	111.1
Genesee	772	71897	107.4	99.9	115.2
Gladwin	27	3098	87.2	57.4	126.8
Grand Traverse	85	10061	84.5	67.5	104.5
Gratiot	56	5592	100.1	75.6	130.0
Hillsdale	40	6523	61.3	43.8	83.5
Houghton	15	4295	34.9	19.5	57.6
Huron	80	4257	187.9	149.0	233.9
Ingham	313	42708	73.3	65.4	81.9
Ionia	94	9024	104.2	84.2	127.5
Iosco	27	3149	85.7	56.5	124.7
Isabella	66	7277	90.7	70.1	115.4
Jackson	210	22839	91.9	79.9	105.3
Kalamazoo	463	34601	133.8	121.9	146.6
Kalkaska	27	2243	120.4	79.3	175.1
Kent	1120	100042	112.0	105.5	118.7
Lake	24	1244	192.9	123.6	287.1

## Mapping of Birth Defects by County

Congenital Heart Defects					
County	Number of cases	Total Live Births	Rate	Lower Confidence Interval	Upper Confidence Interval
Lapeer	135	11982	112.7	94.5	133.4
Leelanau	20	2215	90.3	55.2	139.5
Lenawee	125	13148	95.1	79.1	113.3
Livingston	327	20483	159.6	142.8	177.9
Luce	9	718	125.3	57.3	237.9
Mackinac	15	1317	113.9	63.7	187.9
Macomb	1432	108954	131.4	124.7	138.4
Manistee	19	2679	70.9	42.7	110.8
Marquette	78	7697	101.3	80.1	126.5
Mason	26	3403	76.4	49.9	111.9
Mecosta	57	5092	111.9	84.8	145.0
Menominee	5	2979	16.8	5.4	39.2
Midland	138	11618	118.8	99.8	140.3
Missaukee	22	1899	115.9	72.6	175.4
Monroe	109	19263	56.6	46.5	68.3
Montcalm	93	9007	103.3	83.3	126.5
Montmorency	7	998	70.1	28.2	144.5
Muskegon	230	26081	88.2	77.2	100.4
Newaygo	67	6887	97.3	75.4	123.6
Oakland	3044	176176	172.8	166.7	179.0
Oceana	31	3863	80.2	54.5	113.9
Ogemaw	19	2591	73.3	44.1	114.5
Osceola	43	3167	135.8	98.3	182.9
Oscoda	12	1044	114.9	59.4	200.8
Otsego	34	3068	110.8	76.7	154.9
Ottawa	353	37407	94.4	84.8	104.7
Presque Isle	15	1447	103.7	58.0	171.0
Roscommon	15	2328	64.4	36.1	106.3
Saginaw	533	32699	163.0	149.5	177.4
Sanilac	61	5931	102.8	78.7	132.1
Schoolcraft	5	1041	48.0	15.6	112.1
Shiawassee	73	10315	70.8	55.5	89.0
St. Clair	225	22884	98.3	85.9	112.0
St. Joseph	69	9643	71.6	55.7	90.6
Tuscola	111	7786	142.6	117.3	171.7
Van Buren	119	11659	102.1	84.6	122.1
Washtenaw	703	44127	159.3	147.8	171.5
Wayne	4638	357544	129.7	126.0	133.5
Wexford	32	4317	74.1	50.7	104.6



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